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# Complex Narratives of Individuals Living with Alpha-gal syndrome (AGS). A mixed-methods investigation: examined through self-reported data, in-person interviews, and a group body mapping art therapy intervention

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# Complex Narratives of Individuals Living with Alpha-gal syndrome (AGS). A mixed-methods investigation: examined through self-reported data, in-person interviews, and a group body mapping art therapy intervention

By

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A culminating thesis submitted to the faculty of Dominican University of California in partial fulfillment of the requirements for the degree of Master of Arts in Marriage and Family Therapy

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# Abstract

Alpha-gal (galactose-α-1,3-galactose) Syndrome or AGS is an under-recognized chronic condition which coincides with tick-bite exposure, resulting in a unique allergy to non-primate mammalian products and byproducts (in addition to other items caring the α-gal epitope such as carrageenan, agar-agar, and nori). This paper explores the experiences of individuals with this illness, establishing psychological context for expressed symptomatology, while emphasizing the complex trauma rooted in the population's experiences of the life-altering and life-threatening contexts associated with managing AGS. This research is structured with Acceptance and Commitment Therapy (ACT) theory and utilizes a mixed-methods approach to arts-based research with the goal of establishing a narrative for individuals living with AGS. This transformative approach to arts-based research through the use of the body mapping art intervention will be analyzed alongside in-person dialogues and validated through collected quantitative survey data. The results propose a healing illumination of the experience for the population of concern in addition to the researcher, furthering the benefits of this research through the use of film representation and advocacy. The resulting film serves to directly benefit the AGS population while functioning as a call for support within legislation and increased education across support systems, community members, and health care providers.

**Keywords:** Alpha gal allergy, chronic illness, anaphylaxis, food allergy, red meat, IgE, Tick, galactose, complex trauma, body mapping, art therapy, ACT, MMR, film, advocacy

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To any individual within the AGS community, your experiences do not go unnoticed.

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# Chapter 1: Introduction

Alpha-gal syndrome (AGS) is the leading cause of child and adult-onset allergy and adult anaphylaxis in areas of high prevalence, thus, can be experienced across all ages. This includes much of the Southeast, mid-South, Midwest, and East Coast of the U.S. (Pattanaik et. al, 2018). An individual is "sensitized" to Galα1-3Galβ1- (3)4GlcNAc-R (alpha-gal or α-Gal) if they test positive for the antibody associated with allergies to AGS, alpha-gal immunoglobulin E (IgE). Alpha-gal immunoglobulin G (IgG) and alpha-gal immunoglobulin M (IgM) antibody responses to alpha-gal are documented as beneficial protectants against pathogens such as malaria parasites and tuberculosis mycobacteria and tick bite induced alpha-gal IgE antibodies result in an immune modulation and elevation in anti-α-Gal IgE response (Chmelař et al., 2016; Cabezas-Cruz, 2013).

Nonetheless, sensitization is different from having a clinical allergy to alpha-gal (Kiewiet et. al, 2020**)**. 90% of AGS cases can be diagnosed based on a history of delayed allergic reactions (2-10 hours) after consumption of non-primate mammalian meat (such as cows, pigs, lambs, rabbits, buffalos, bison, and kangaroos) or mammalian-derived products and a positive (>0.1 IU/mL) alpha-gal IgE blood test (Commins et al. 2009; Commins et al., 2016; Steinke et al., 2015; Sharma and Karim, 2021). AGS requires more than an avoidance of eating red meat and psychological strength. Ingestion, topical, and inhalation of the alpha-gal epitope can result in immediate and 0-10 hours after exposure for AGS patients. Those living with AGS are impacted autonomically, muscularly, mentally, and behaviorally by this allergy as they navigate daily life (Platt & Merritt, 2022).

While only some people who are sensitized to any allergen will have a clinical allergy to it, the estimated percentage of the population with a clinical alpha-gal allergy is shockingly high

(Alpha-gal info, 2022). A 2022 University of Virginia study determined 1-3% of the population as having a clinical allergy to alpha-gal where lone star tick populations are high. While AGS is not limited to these states, the population of Virginia, North Carolina, Kentucky, Tennessee, Arkansas, and Missouri combined is about 40 million people. Thus, it is possible that more than a million people in the United States have AGS, many undiagnosed or misdiagnosed (Commins, 2020; Richards et. al, 2022)**.**

The Centers for Disease Control and Prevention (CDC) broadly labels chronic illnesses as:

> *Conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both. Chronic diseases such as heart disease, cancer, and diabetes are the leading causes of death and disability in the United States. They are also leading drivers of the nation's $3.8 trillion in annual health care costs (CDC, 2021).*

Even though alpha-ga is the leading cause of adult anaphylaxis, the disease is not limited to age and the potential impact of AGS on children and families should not be bypassed (Commins, 2016). Food allergy is a common chronic condition, affecting 32 million Americans, 5.6 million being children. One in three children report being bullied as a result of their food allergies and caring for a child with a food allergy is also associated with poorer mental health (Morris et. al, 2012; Sincherer & Hugh, 2018). Previous literature has shown that parents of children with food allergies reported higher stress, anxiety, and depression compared to parents of children who do not (Birdi et. al, 2016). Food allergies can majorly affect the lives of those who carry it. These families experience a shift in social lives, often leading to isolation, depression, and anxiety. Food allergies lead to a loss of normalcy, requiring families to adjust decision making and routines for the sake of their child's health management (Feng & Kim, 2019). Additionally, food allergies cost U.S. families roughly $25 billion annually (Food Allergy Research & Education, 2022).

The increasing cases of individuals with AGS in addition to rising cases in childhood allergy has revealed an underrepresented but prominent need for supplementary research. The novel experience of a developed immunoglobulin E (IgE) antibody response to the transmitted carbohydrate molecule, galactose-α-1,3-galactose (alpha-gal), expands on previous perceptions of food allergies and challenges those managing it. When individuals with AGS eventually receive a diagnosis, they are met with unclear treatments and insufficient medical backing (Hinds & Sutcliffe, 2019). They then can endure a lack of access to medical care and resources in addition to facing a society that is taking damaging steps against their daily management due to an overarching deficiency in knowledge and understanding of this chronic health condition. The lack of support for these individuals in combination with poor regulations on personal products makes avoiding allergic reactions difficult to achieve. This also calls into question the ways individuals cope with AGS in addition to the structure implemented to support their safety.

## Chronic Illness

Those living with chronic illness display fifty percent higher odds of survival with strong social relationships (Hors-Fraile et.al, 2016). Additionally, individuals living with chronic illness may seek support through online groups to gain this sense of community and understanding. Social media helps create visibility and community by providing a platform for individuals to connect through experience. Sharing stories and tips for managing chronic illness can raise awareness, destigmatize conditions, and can make the adjustment less intimidating for someone who is newly diagnosed. While there are clear benefits, it is also important to acknowledge that they are not supplementary to the policy changes and resources needed to best support the AGS community. Online groups also pose risks in possibly increasing negative feelings, maintaining privacy, and spreading misinformation which may result in added stress (Hors-Fraile et.al, 2016).

Stress management is an important element to chronic disease management as it is strongly linked to inflammation. When perceptions of stress are heightened, the body's inflammatory response is intensified, worsening disease symptoms (Hirsch & Sirois, 2014). Documenting a correlation between AGS and perceived stress will begin to establish concrete data on the severity of mental health symptoms that can be associated with this life altering condition. Additionally, due to the layered element, individual The Perceived Stress Scale (PSS), developed by Cohen and Kamarck in 1983, is a popular tool in understanding how different situations affect one's feelings and perceived stress. Yet, the lifestyle shift that occurs alongside chronic illness can affect an individual's identity on many levels that go beyond the psychological perception (conscious and subconscious) of stress.

**ACT and Stress**

Dr. Bessel van der Kolk defines trauma as "an overwhelming experience that deeply disturbs us inwardly and continues to negatively affect how we view and relate to ourselves, and to everything else in our world" (Van Der Kolk, 2014). Traumatic stress compromises the body's immune system, weakens its response, and can further complicate disease management (Varadarajan et. al., 2022). When an individual experiences stress, the brain perceives and determines the psychological and physiological response to the internal or external stressor. This mind-body relationship ultimately creates an immune alteration which can affect all systems of the body including musculoskeletal, respiratory, cardiovascular, endocrine, gastrointestinal, nervous, and reproductive systems (Shaw et. al., 2019). Anaphylaxis in itself can be considered a traumatic event. A meaningful proportion of those who experience it, including children and their parents, display stress symptoms following the event (L, 2020). Thus, the implications of neglecting individuals with AGS in terms of failing to meet their basic physical and emotional needs over time, will have damaging effects on their lives as well as the individuals who support them.

Within medical treatment, the body is a central point of interest between the patient and physician. One's dependence on the body can reveal itself through their life journey and the navigation of trauma. Therapeutic treatment aims to dissect a wider range of emotional elements that can be associated with managing life circumstances. The relationship between an individual's mind and body is a core element in how Acceptance and Commitment Therapy (ACT) developed from Cognitive Behavioral Therapy in the late 1980s by the work of Steve Hayes, Kelly Wilson, and Kirk Strosal (Smith, n.d.). Rather than attempting to change the personal, social, geographical, political, and emotional experiences one endures, ACT begins with acceptance of one's reality alongside their thoughts. Ultimately, this mindfulness-based therapy encourages individuals to develop more meaning and purpose to life by bringing positive changes. This is done by understanding how to develop a relationship with their struggles through an inquisition of their thoughts alongside personal values.

Cognitive fusion refers to when thoughts and experiences become indistinguishable from one another. Cognitive defusion (CD) is a form of de-literalization. Within Acceptance and Commitment Therapy (ACT), CD is utilized to distance an individual from their thoughts by viewing them subjectively (Hayes, et. al, 2012). The benefits of cognitive defusion include increased mindfulness of direct experience (i.e., feelings, sensations, etc.). This distancing in combination with use of metaphor can help individuals understand the depth of their reality rather than becoming stuck on painful and self-defeating thoughts (Bennett & Oliver, 2019).

## Art Therapy and Body Mapping

Art therapy has shown to be an effective tool for improving quality of life while reducing symptoms of depression, anxiety, stress (Keser, 2016). The goal of art therapy aims to uncover an individual's unconscious, as a means for deepened personal understanding and healing, through utilizing a continuum of mediums and directives. Art creates visual symbolization for individuals to express what is experienced. Art often becomes a reflection of the creator by establishing a sense of clarity and control through the construction and projection process. For the purpose of this research, art therapy is a form of phenomenological inquiry. The arts-based qualitative data will be gathered and presented with emphasis on the autonomy of participants as narrators of their lived experiences over the researcher's attempt to analyze and describe.

Body mapping, designed by Jane Soloman in 2008, originated as an aid for individuals with serious health concerns (Solomon, 2008). The art therapy directive displays success in documenting and connecting communities through the consideration and visual expression of autobiography. Solomon's original intention of establishing context for expressing and connecting narratives of frequently bypassed individuals has further succeeded in empowering participants in their healing journey by creating a discussion for political advocacy. This body mapping research will expand on what began as an expression of what it is like to live with HIV and AIDS through the expression and consideration of the socio-cultural context for individuals living with AGS. Collected data will be represented in a collaborative film to directly aid and connect the population of concern, raise public awareness, and call to action the relevant need for further social action.

The call for social action and increased awareness surrounding AGS is overdue. As of 2017, Flaherty et. al. documented just over seven years as the average time for almost eighty percent of participants to receive a correct AGS diagnosis. It is promising that the timeline for diagnoses will decrease as cases and public awareness increases. However, this requires an avenue for information to be spread effectively. When healthcare providers and legislation fail to properly support their condition, patients with AGS establish a new trust and aid through other sources such as friends, news, online searches, and social media groups (Platt & Carrison, 2019). Part of this study will include developing a film as an advocacy tool for the AGS community. In order to best advocate for those living with this condition, the film will focus on capturing and connecting the individual experience of participants. More specifically, the shared perception of thoughts and senses surrounding living with AGS will be the overarching displayed narrative. The final product of the film will be a collaboration between the researcher and the participants through what is expressed. It will be shaped around revealed themes of overlapping and differentiating mind-sets expressed through shared opinions, interpretations, and chosen words of advice given to individuals who are newly diagnosed with AGS.

## Research Question

This research will examine the participants' narration of their body maps through the six basic principles of ACT: cognitive defusion, expansion and acceptance, contact and connection with the present moment, observing self, clarifying values, and committed action. This multi-dimensional study will attempt to document several aspects that precede individuals with AGS through a mixed methods approach of quantitative surveys, and qualitative art representation as an aim to expand on the sparse existing research of this population.

This research project seeks to capture the experience and feelings of stress, isolation, and neglect of individuals with Alpha-Gal Syndrome (AGS) and how connection to community serves as a valuable tool to combating these concerns, displayed through body mapping and collaborative film. Thus, the purpose of this investigation will be to determine if body mapping will reveal overlapping themes of experience through qualitative analysis. The data and phenomenological themes of living with AGS will be translated into an accessible film for patients, caretakers, peers, and policy makers. Lastly, the results of this study will contribute to further developing, strengthening, and establishing validity within the field of art therapy.

## Conclusion

Above all, supplemental research is needed to better understand the psychological and pragmatic experiences for individuals living with AGS. This tick-borne illness is life-altering and life threatening as the elements to managing AGS are greater than a typical food allergy. Documenting levels of perceived stress and lived experience will serve as valuable tools for patient advocacy. Improved awareness and education for AGS will reduce the risk of misdiagnosis. Additionally, it will contribute to the push for furthering supportive AGS specific legislation, such as increased labeling on products that may not be considered as hazardous to the general public. Furthermore, as the public gains awareness of the profound implications of this condition, more support will be established for individuals living with AGS, ultimately improving the safety and quality of their lives.

# Chapter 2: Literature Review

## History of Alpha-gal

It is important to note that alpha-gal syndrome has emerged more recently within the field of medicine, creating a need for expanding existing biological and mental health literature on this topic. While there is documentation of at least two groups reporting an onset of meat allergy after tick bites in late 2000, it wasn't until 2005 in which AGS introduced itself into the field of medicine during the first infusion of cetuximab in clinical trials (Alpha-gal info, 2022). In 2007 the number of patients experiencing extreme reactions to cetuximab continued to climb as two cases of delayed anaphylaxis after eating beef were reported (Tick and Mammalian Meat allergy, 2021). In 2008 alpha-gal IgE antibodies were linked to cancer patients who received cetuximab (Chung et al., 2008).

The reactions to cetuximab resulted in lowered blood pressure, difficulty breathing, emergency shots of epinephrine and hospitalization for some, and death for a patient in Bentonville, Arkansas. Ultimately, a team of researchers in Virginia including Dr. Thomas Plats-Mills, Dr. Tina Hatley, Dr. Scott Commins, and several others identified the sugar galactose alpha-1, 3-galactose (alpha-gal) to be the link after an association between the number of cases and areas of prevalent Rocky Mountain spotted fever was made (Commins et al. 2009; Dahlgren et al., 2016; Tick and Mammalian Meat allergy, 2021). Dr. Sheryl van Nunen found a link between red meat allergy and ticks in Australia in 2007, though it wasn't until 2009 when the research team became aware of this finding (Alpha-gal info, 2022). Since then, Alpha-gal reactions have been documented globally except for the Arctic and Antarctic. AGS has also been associated with bites from at least ten species of ticks and chiggers (redbugs, harvest mites, etc.), including the lone-star tick (Stoltz, 2018).

## Diagnosis, Reactions, and Anaphylaxis

AGS is understood as a type of allergy which involves an IgE antibody response. The unusual aspect to this allergy being that IgE-mediated allergies typically result in clinical symptoms less than thirty minutes after exposure whereas AGS can be immediate or delayed 2-10 hours (Commins et al. 2009; Commins et al., 2016; Steinke et al., 2015; Sharma and Karim, 2021). Researchers believe the delayed response is largely due to the way the associated glycolipid is metabolized and is also correlated to how meat digestion, absorption, transport, and occurs within the immune system (Steinke et al., 2015; Platts-Mills et al., 2015b; Sharma & Karim, 2021). The blood test for AGS which identifies the Ig-E antibodies specific to alpha-gal has been available since 2010 (Viracor-IBT Laboratories in Lee's Summit, Missouri; Binder et al., 2021). Yet, the most used allergy tests consist of skin pricks which do not accurately identify an alpha-gal allergy. Moreover, the overarching lack of education in addition to the idiosyncratic and delayed feature of this illness challenges previous understandings of food allergies, making it difficult for patients to receive a diagnosis for their experiences (Flaherty et al., 2017).

Narrowing down a diagnosis can be traumatic, especially when it involves life-threatening illness, invasive medical procedures (Hall & Hall, 2013). The life-altering effects and feelings of powerlessness that come forward during this time of uncertainty suggest an importance for addressing common psychological and emotional impacts of medical trauma (Hall & Hall, 2013) in addition to the daily experiences of managing AGS. Unfortunately, during and after concluding their search for answers, patients continue to experience severe and sometimes fatal reactions. Patients with AGS experience a range and variety of reactions (Fischer, et al., 2016). Specific symptoms include urticaria (hives, welts, or nettle rash), angioedema (swelling underneath the skin), pruritus (itchy skin), and systemic anaphylaxis.

Some patients also report more immediate nausea, indigestion, diarrhea, and abdominal discomfort before AGS onset while others report experiencing none of the above (Platts-Mills et al., 2015b; Wilson et al., 2017). Other clinical responses which need to be investigated further include reports of abnormal neuro-psychiatric behavior (abulia, aphasia, abnormal gait, and reduction of limb movement; (Wuerdeman & Harrison, 2014) as well as spontaneously resolving palpitations and tachycardia (Daripa & Lucchese, 2022; Vas-Rodrigues et al., 2022).

While it is stated in reference across AGS literature, the most severe reaction to alpha-gal is anaphylaxis (CDC, 2022). Anaphylaxis requires immediate medical treatment as this over-release of chemicals is both shock inducing and life threatening. Warning signs may include: red rash, swelling of the throat or areas of the body, wheezing, rapid or weak pulse, dizziness or passing out, chest tightness, difficulty breathing, coughing, hoarse voice, drooling or trouble swallowing, vomiting, diarrhea, stomach cramping, pale or red coloring to face (warmth/flushing) and/or body, and feeling of impending doom (Allergy Asthma & Immunology, 2022; Mayo Clinic, 2022). It is also possible for a second anaphylactic reaction, or biphasic reaction, to occur up to twelve hours after the first occurrence. Yet, AGS patients, alongside all individuals who experience anaphylactic reactions, will continue to remain at risk for future anaphylaxis daily regardless of treatment with self-administered epinephrine and hospitalization (the American College of Allergy, Asthma, & Immunology, 2022).

## Management

Anaphylaxis reactions may require fluid resuscitation, vasopressors, and intubation in addition to intravenous epinephrine (Mchugh & Repanshek, 2022). In order to reduce risk of fatality, treatment for AGS requires an incorporation of both medical and nonmedical daily management. Non-medical management interventions center around avoidance, tick bite prevention, wearing medical alert bracelets, and education surrounding exposures (i.e., hidden exposures in nutrition fact, risk for ingredients within both personal care and pharmaceutical products, manufacturing processes, etc.). Medical management pertains to clinical treatments such as carrying self-administered epinephrine and self-medicating for symptoms with medications such as oral antihistamines, corticosteroids, lying down with elevated legs, and cold compresses. Patients may also make note of several studies which identify a handful of elements which can exacerbate the severity of reactions (i.e., alcohol, physical exercise, use of non-steroidal analgesic drugs, and menstrual cycles; Wölbing et al., 2013; Fischer et al., 2014; Versluis et al., 2016). Alternatively, there is also promising and developing research within non-traditional methods to combat allergies with cannabinoids (Angelina et al., 2020).

### ***Tick Prevention***

While there are a few optimistic reports of symptoms lessening and even disappearing over time, there is no certainty as to why additional bites can also increase sensitivity levels (Commins et al., 2011; Levin et al., 2019). Lone star tick bites can occur year-round (Fonseca, 2018), most commonly in the early fall and late spring (CDC, 2022). Deer have been noted as the primary host for the Lone Star Tick, though it is important to note that high populations of ticks are found in wooded, bushy areas with long grass (Molaei et al., 2019). The Mayo clinic suggests covering up (i.e. wearing long pants and tucking them into socks, full length sleeves, a hat, and gloves), remaining on trails with any accompanying pets, using insect repellents and permethrin infused clothing, clearing your yard of brush and leaves (moving these piles into sunny areas), checking for ticks after hikes, showering with a washcloth immediately after outings, and carefully removing any ticks with tweezers and antiseptic as soon as possible (Mayo Clinic, 2022).

### ***Avoidance***

Following tick-bite exposure, the primary piece of information patients receives in regard to managing AGS is to avoid mammalian meat such as cows, pigs, lambs, rabbits, buffalos, bison, and kangaroos (Commins, 2016). However, alpha-gal is found within a large variety of foods, products, and manufacturing processes which do not always indicate adequate labeling disclosures. AGS patients should also be made aware of risk with pork gut casings for sausages, mammalian fat in foods (often found in gravies and sauces for added flavor), Gelatin (derived from collagen and used within jellybeans, marshmallows, puddings, contact lenses, shampoo, tattoo ink, etc.), stocks and bouillon cubes, and carrageenan (extracted from red edible seaweeds and is used as a thickening agent). Specific medical uses which contain mammalian proteins or parts are listed as the following: monoclonal antibodies (used to treat infection), gelatin-containing medications (i.e. the capsules that incase many medicines), enzyme replacement for diseases such as cystic fibrosis, bovine or porcine heart valves, anti-venom and various vaccinations (e.g. acetaminophen, oxycodone, lisinopril, and oxycontin), heparin, and hormone therapies (e.g. thyroid, oral birth control pills, etc.) (Office of HIV/AIDS and Infectious Disease Policy, 2022; Commins, 2020).

As one dissects the range and uses for the products listed above, they may come to understand the level of difficulty it is to achieve full avoidance, especially given that many of the medications are frequently used within emergency medical procedures and products that one may not associate with a meat allergy (Commins, 2020). There is no current research which pertains to specific AGS fears elicited by the possibility of medical responders lacking knowledge of this illness. However, one suggestion for combatting the concern, aside from increased education, could be to provide suggestions to patients on labeling medical alert badges in the event they are in need of emergency medical attention. Given the expressed research, experts will need to establish the most beneficial warnings for AGS patients to disclose. Nonetheless, due to the expressed prevalence, it is vital for patients and doctors to be aware of medical risks.

### ***Misleading Information and Byproducts***

The CDC (2021) discloses valuable information regarding vaccinations and makes explicit notes of the concern for gelatin, glycerin (also found in many skin care products; Becker et al., 2019), magnesium stearate, and bovine extract. Yet, the webpage is misleading in disclosing poultry (chicken, turkey, duck, or quail), eggs, seafood (fish and shrimp), and fruits and vegetables to not contain alpha-gal as it is possible for many of these items to trigger an allergic response due to the manufacturing processes they undergo (Dey & Nagababu, 2022). For example, if someone with AGS consumes chicken, they could be at risk for cross contamination if other mammalian meat is processed with the same equipment or on the same line in addition to if the bird was given any antibiotics treatments which contain the alpha-gal epitope. Further research is needed to determine the reported links between chicken eggs and alpha-gal reactions (Alpha-gal Information, 2022)

Currently, the Alpha-Gal Information page (2022) lists the most extensive data on these types of product risks, making it a valuable resource for AGS patients to access and be aware of. AGS requires a heightened awareness of the potential threat from processors and manufacturers. Ground turkey is often processed with additives to keep the color fresh which can raise a concern and fish can undergo carrageenan or gelatin agents. Even “Kosher” products are not entirely alpha-gal safe. Until food professionals are required to label all processing agents, animal byproducts, stabilizers, and "natural ingredients" by a clear and recognizable name, the risk for anaphylaxis due to hidden exposures remains a threat to the AGS population.

### ***Not so "Vegan": Carrageenan, Sugar, and "Natural Flavoring"***

When considering AGS management, one could conclude that a vegan lifestyle change may be the solution to alleviating risk for exposure. However, this is not necessarily the case as labeling regulations remain unclear for consumers on many vegan products. As mentioned above, carrageenan is derived from red algae, yet it also contains the alpha-gal epitope (Tobacman, 2015). Items with added sugar pose a threat when they are "non-organic" as they often go through a refining process that contains mammal bones (PETA, 2015). Additionally, beavers emit a "goo" called castoreum from their anal glands. Castoreum gives off a "natural" musky vanilla scent, making it an appealing additive to flavoring (e.g., raspberry and vanilla flavoring, baked goods, beverages, etc.), and perfumes (Burdock, 2007).

Any product containing carrageenan, sugar, and "natural" ingredients can also be labeled as vegan. The FDA's regulations and use of umbrella terms such as "natural," "vegan," and "plant-based" lack specificity, making it difficult for any consumer to evaluate the exact ingredients they are purchasing or if they are mammal-free (Yacoubau, 2018). Unfortunately for individuals with AGS, this lack of specificity, in combination with the simple act of enjoying a can of sparkling water, could be the difference between life and death.

Lecturer on Law and Clinical Instructor (Harvard Law School Animal Law and Policy Clinic), Nicole Negowetti, discusses the role of the FDA and The Federal Trade Commission in regulating food safety in her 2021 Oregon Law Review (p.117) stating:

> *The Federal Trade Commission (FTC) and the FDA have overlapping jurisdiction to regulate the advertising and labeling of foods. Section 343(a) of the FDCA*

> *prohibits the "misbranding" of food, which includes labeling that "is false or misleading in any particular."127 Section 5 of the Federal Trade Commission Act prohibits "unfair or deceptive acts or practices,"128 and § 12 and § 15 of the Federal Trade Commission Act prohibit "any false advertisement" of food products that is "misleading in a material respect." This shared jurisdiction over labeling and advertising of food products operates pursuant to a longstanding Memorandum of Understanding between the agencies. Under this agreement, the FDA exercises primary responsibility for regulating food labeling, while the FTC assumes primary responsibility for ensuring that advertising food products are truthful and not misleading. (Negowetti, 2020)*

Thus, it is logical to argue where the FDA and FTC may be failing in their legal obligations towards the alpha-gal population due to the broad range of inconsistent and deceptive labeling.

### *Medical management*

Many studies list commonly prescribed medications (non-containing gelatin or gelatin capsules) for managing symptoms. For example, patients may choose to implement the use of oral antihistamines if they have concern for encountering something like smoke from a grill. Other medications which have shown to be useful in differing scenarios include oral cromolyn solution (a mast cell stabilizer for gastrointestinal symptoms), oral corticosteroid (prescribed for patients with asthma), omalizumab (for symptoms consistent with 'mast cell activation'), and metformin (used in preparation for gastric bypass surgery; Commins et al., 2020).

### *Antihistamines and Serotonin Syndrome*

Studies indicate histamines to have a strong influence on serotonin in the brain (Samaranayake et al., 2016; Threlfell et al., 2004; Schlicker et al, 1988; Fink et al., 1990), evoking histamines and serotonin to be markers of inflammation and chronic stress. While stress does not inherently cause allergies, it can increase the body's histamine release into the bloodstream, making allergic reactions more severe. (Hersey et al., 2022). Daily use of antihistamines may be an appealing strategy in managing alpha-gal symptoms. Research has also linked long term use of Benadryl or diphenhydramine (and other anticholinergic medications) with an increased risk for dementia (Gray et al., 2015). Abruptly stopping use of antihistamines can result in withdrawal symptoms similar to opioid addiction. This seems to be a common thread across treatment facilities despite a severe lack of literature documenting this experience (Farzam, n.d.; CirqueLodge, 2022). Additionally, diphenhydramine can increase levels of serotonin in the brain. This raises concern for individuals taking selective serotonin reuptake inhibitors (SSRIs) to develop serotonin syndrome (Graden, 2021). Serotonin syndrome can be life-threatening and includes symptoms of agitation, confusion, hallucinations, fever, sweating, shivering, muscle stiffness, loss of coordination, nausea, vomiting, and diarrhea (Khan et al., 2018). Existing case studies are alarming yet limited in validating this potential side effect, requiring further exploration and additional reports (Schwartz et al., 2007; Tanaka et al., 2011).

### ***Cannabinoids***

Within the endocannabinoid system, there are two primary cell receptors found on the surface of cells: Cannabinoid Receptor 1 (CB1) and Cannabinoid Receptor 2 (CB2). CB1 is associated with pain and CB2 with the immune system cells (Angelina et al., 2020). Tetrahydrocannabinol (THC) binds to both CB1 and CB2 receptors while the benefits of cannabidiol (CBD) are seen through more indirect actions (Corroon & Philips, 2018). Cannabinoids have demonstrated an ability to modify the activity of the immune system, and in turn decrease the body's inflammatory response and alleviate pain (De Filippis et al., 2008).

However, research does not express an effectiveness in the binding affinity of CBD without THC, implying the medical benefits for allergy treatment and inflammatory response pertains predominately to THC (Giudice et al., 2007; Posival, 2016).

Mast cells release histamine and other factors which contribute to an inflammatory reaction. Evidence has been published on medical used cannabis suppressing mast cell degradation, suggesting use of THC to be a novel treatment for AGS patients (De Filippis et al., 2008). A 2019 study discusses how several research studies have exhibited cannabinoids to have anti-inflammatory properties in the airways and skin on both mice and humans (Bozkurt, 2019). Future studies are needed to expand understanding of exactly how cannabinoids function within immune responses. Yet, the existing literature displays promise for use of cannabinoids within chronic inflammatory and allergic disease treatment (Martin-Fontecha et al., 2014). In addition to consulting an allergy specialist, individuals with AGS considering the use of THC should also evaluate possible cross-contamination and byproducts which can be present within numerous marijuana products (e.g. manufacturing processes, adhesives on rolling papers, cross contamination from others if utilizing products within a social setting). Additionally, individuals may want to understand how the effects of cannabinoids can differ (positively, negatively, and detrimentally) depending on the compound utilized, how the compound is administered (i.e. edible, smoked, vaped), frequency and quantity of use, age of user, and any genetic mental illness predispositions (Owens et al., 2022; Petrilli, et al., 2022).

## Alpha-gal response and Inflammation

Inflammation is the body’s response to danger or damage. Acute inflammation can be beneficial and refers to the immediate response working to protect against infection (Hannoodee & Nasuruddin, 2021). Chronic inflammation is more prolonged (Pahwa et al., 2022). Over time, chronic inflammation can cause cellular damage, increasing the risk for illness (Yang et al., 2015). The anti-α-Gal-specific IgE response has been correlated with a increasing number of diseases including Alzheimer's disease (Angiolollo et al., 2021), atopy (i.e. allergic rhinitis, asthma, and atopic dermatitis or eczema), atherosclerosis, and coronary artery disease (Gonzalez-Quintela et al., 2014; Wilson et al., 2017, 2019). While this does not mean AGS results in these illnesses, there is evidence of inflammation being a well-known process within many infectious and non-infectious diseases (Hunter, 2012). Additionally, research displays evidence for chronic inflammation being the cause of numerous diseases (Pahwa et al., 2022).

Exposure to allergen(s) causes inflammation and continued or repetitive exposure leads to the development of chronic allergic inflammation (Galli et al., 2008). In addition to the medical application, inflammation has been displayed as a likely risk factor for every psychiatric disturbance (Miller et al., 2016). This research does not elude inflammation to be the root of mental illness rather than a possible cause related to a given individual's condition. Thus, the implications of the effects of inflammation within chronic and mental illness needs to be understood through the specific patterns of brain functioning and life circumstances.

## Trauma

The American Psychological Association ascribes trauma to be:

> *Any disturbing experience that results in significant fear, helplessness, dissociation, confusion, or other disruptive feelings intense enough to have a long-lasting negative effect on a person's attitudes, behavior, and other aspects of functioning. Traumatic events include those caused by human behavior (e.g., rape, war, industrial accidents) as well as by nature (e.g., earthquakes) and often challenge an individual's view of the world as a just, safe, and predictable place (APA, 2022).*

Each element of managing AGS contains potential stressors and risks for experienced trauma. The effects of living with life-threatening allergies, such as AGS, can create significant discomfort, stress, and fear. A study found the average length of time for an AGS patient to receive a diagnosis to be seven years. Seven years of searching for answers equates to 2,555 days of suffering alongside a series of often painful and invasive medical procedures. Anaphylactic shock, or anaphylaxis, can be considered a traumatic event and even result in post-traumatic stress disorder, anxiety, and/or depression. When an individual experiences anaphylactic shock it is common for sadness, nervousness, worry, fears, and guilt to arise. Due to the lack of education surrounding AGS and the number of medications and equipment which can trigger anaphylaxis in this population, there is potential for many AGS patients to also develop a distrust (or a legitimate fear) in hospitals and doctors due to experiencing significant medical trauma. Traumatic events are not limited to the individual who endures them and can affect anyone perceiving them.

## Complex Trauma

Post-traumatic stress disorder (PTSD) is common across high-stress occupations and is typically caused by listening, witnessing, or experiencing a traumatic event (Rauvola et. al, 2019). These events can often be attributed to natural events, accidents of fate, death, global crisis, etc. (Karatzias et. al, 2017). Alternatively, complex trauma or CPTSD is caused by on-going trauma and frequently associated with interpersonal dynamics where there is a struggle to navigate and maintain effective physical/emotional boundaries due to conflicting power dynamics (i.e., one individual is dependent for physical/emotional safety. Cloitre et. al, 2013; Davis et. al, 2023). There is a disagreement in labeling complex trauma across the field of psychology where CPTSD is listed in the International Classification of Diseases (ICD-11) but not under the same term within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; Karatzias et. al, 2017). Regardless, overlapping symptoms between PTSD and CPTSD include re-experiencing trauma from triggered memories/experiences, avoidance of reminders of trauma, alterations in mood and thinking, and feeling more on edge (Cloitre, 2020). Individuals with CPTSD have reported additional symptoms such as long-term difficulties in maintaining relationships, difficulties managing emotions, strong feelings of worthlessness and guilt, physical symptoms (headaches, chest pains, and stomach aches), and suicidal thoughts (Torres et. al, 2023).

Treatment for PTSD can be found within trauma-focused therapies such as eye movement desensitization and reprocessing (EMDR) and cognitive behavioral therapy (CBT; Khan et. al, 2018). Both EMDR and CBT encourage the client to recall and process past events in a safe and controlled environment to guide the transformation of negative thoughts, feelings, behaviors, and beliefs into positive and healthy alternatives (Lancaster et. al, 2016). These treatments can also be implemented for treating CPTSD (Khan et. al, 2018). However, PTSD treatments have been shown to be effective in 8-12 sessions whereas CPTSD sometimes requires more than six months of regular and recurring sessions (Darnall et. al, 2021; Davis et. al, 2023). This is because CPTSD requires an element of skill-building in learning how to manage strong emotions, create supportive relationships, and address feelings of worthlessness and guilt associated with prolonged trauma and more ingrained behaviors Jensen et. al, 2022). Additionally, the longer an individual endures CPTSD, the more rigid they may become in their defenses (Cruz et. al, 2022). Collaboration encourages and reinforces a client’s agency (Castañer & Oliveira, 2020). Furthermore, collaborative and creative models display strength in promoting an open dialogue through encouraged partnership and trust between the clinician and client for individuals with CPTSD (Davis et. al, 2023).

## Stress

Increased inflammatory activity has been associated with both acute and chronic stress (Maydych, 2019). The National Institute of Health (PDF) defines stress by “how the body and brain responds” to demands. Stress is beneficial when physical and psychological efforts are able to combat a given challenge, re-establishing homeostasis. However, when the demands exceed an individual’s adaptive capacity, there is a direct effect on the biological processes and behavioral patterns which impact disease (Mariotti, 2015). Prolonged stress weakens the body’s immune system, contributes to the development of various pathological conditions and diseases, and complicates existing disease management (Yaribeygi et al., 2017; Varadarajan et. al., 2022). This process can affect every system in the body, raising concern for the impact of stress on the musculoskeletal, respiratory, cardiovascular, endocrine, gastrointestinal, nervous, and reproductive systems in addition to the psychological impacts (Shaw et al., 2019).

### *AGS Stressors*

Numerous studies discuss a range of factors which increase the risk for heightened stress. These factors include but are not limited to gender, community, race and ethnicity, socioeconomic status, ability, and age (Mayor, 2015; Mozumder, 2017; Byrd & McKinney, 2012; Eva & Thayer, 2017; Kabat-Zinn, 2013, Crowley & Munk, 2017). Chronic illness alters engagement with daily tasks and functioning. It also often results in numerous visible and invisible symptoms. Research expresses individuals with chronic medical conditions to be at higher risk of mental illness, predominantly depression, anxiety, adjustment disorders (pertaining to children and adolescents), and PTSD (National Institute of Mental Health; Koenen & Galea, 2014). Dr. Paige Freeman expresses living with AGS to be immensely stressful for a variety of reasons. The stressors that occur as a result of AGS can pertain to and go beyond the following categories: reactions and anaphylaxis, avoidance of the allergen, financial burden, social, interpersonal, familial stressors, delayed reaction, lack of familiarity with AGS in the medical community leading to delayed diagnosis and navigating conflicting and/or lack of information (Freeman, 2021).

### ***Perceived Stress and Personality***

Stress is an unobservable yet cross-cultural symptom across many health conditions (Vallejo et al., 2018). Perceived stress can be understood by an individual's thoughts or feelings pertaining to the amount of stress they experience at any specific point or over a period of time (Philips, 2013). Perceived stress measures coping of stress rather than the frequency of occurrence. Stressors perceived as greater threats trigger stronger stress responses than lesser threatening characteristics. This study focuses on revealing narrative and experience alongside the documentation and evaluation of perceived stress in participants affected by AGS, researchers have been exploring how different personality traits can allude to how an individual perceives, copes, and responds to a given event. While more extensive research is needed, numerous psychological studies have examined how health can be consequently altered by personality (Magee et al., 2013; Turiano et al., 2012). A 2016 study (Shields et al.) interrelates pessimism with increased stress, discussing several studies which have linked greater levels of pessimism to numerous negative outcomes (e.g., social disruption, poorer life quality, elevated inflammation, and early mortality). Lifestyle disruptions, such as the COVID-19 pandemic, can further impact stress levels of individuals with chronic illness by negatively impacting disease management and access to care (Kendzerska, 2021). The specific biological, social, and psychological factors of stress pertaining to AGS patients have yet to be investigated.

### ***Perceived Stress Scale***

Researchers examine stress through several aims: environmental factors, psychological appraisal, and biological responses. The Perceived Stress Scale (PSS) is a self-reporting psychological questionnaire based on the concept of cognitive appraisal by Richard Lazarus. This theory suggests an individual's reactions are caused by their appraisal or evaluation of a given event (Lazarus & Folkman, 1984). Dr. Sheldon Cohen structured the original PSS as a fourteen-item questionnaire (PSS-14) and was initially intended solely for the purpose of researching and measuring stress (Taylor, 2015). Over the years, the PSS has become one of the most widely used measurement instruments for evaluating psychological distress and understanding intervention effects (Galante et al., 2021; Makhubela, 2020). Several years after the PSS-14 was released, a shortened ten item scale (PSS-10) was developed in addition to a four-item scale (PSS-4) (Cohen et al., 1983; Cohen & Williamson, 1988). Of these three versions, the PSS-10 is arguably the most frequently used, contains the strongest psychometric properties, and is translated into over twenty-five languages (Makhubela, 2020). While the PSS is employed globally, test-retest reliability, criterion validity, and known-groups validity for English and non-English versions requires further investigation and evaluation (Lee, 2012).

Lazaurs and Susan Folkman acknowledged the experience of stress to be unavoidable but varied due to personal interpretation of surroundings, well-being, and capability. In their book *Stress, Appraisal, and Coping* (Lazarus & Folkman, 1984), Lazuarus and Folkman state the initial interpretation of an event’s relevance, harm/loss, threat, or challenge to occur within *primary* appraisal while *secondary* appraisal pertains to the decision making, coping, and evaluation of the event. Additionally, they believed individuals would ultimately respond and cope through solution seeking or self-regulation attempts (p. 44). While many psychological and physiological illnesses can be associated with stress, Cohen et al. emphasized the use of the PSS as a measure rather than a predictive instrument (1983). Stress levels fluctuate daily and are less reliable when evaluating long-term health (Epel et al., 2018). Understanding how an individual interprets and expresses their narrative may be needed to fully comprehend the nuances and details of one's experience and needs (Wang & Geale, 2015). Understanding how an individual interprets and expresses their narrative may be needed to fully comprehend the nuances and details of one's experience and needs (Wang & Geale, 2015).

### Reappraisal and Acceptance

In most situations, individuals seek solutions when a sense of understanding and ability to alter the stressor is achievable whereas emotion-focused coping is used in regulating responses for an uncontrollable stressor (Lazarus and Folkman, 1984). Problem focused interventions contain the risk of bypassing previous negative thoughts or feelings that accompany previous trauma. Conversely, emotion-focused coping encourages reappraisal or reconsideration of a situation, creating opportunity for individuals to alter appraisals that contribute to negative emotions (Gross, 1998; Lazarus & Folkman, 1984). The process of reappraisal occurs consistently as an individual reevaluates and processes their experience.

Troy et al. (2018) discusses how reframing one's thoughts (reappraisal) and accepting feelings without judgment or attempted control (acceptance) to have positive psychological health benefits over time. Reappraisal becomes more difficult as the intensity of a situation increases (Ortner et al., 2016). An extensive review of the literature expresses reappraisal to have effective and beneficial short- and long-term effects on experienced emotion (positive and negative). Though less is known about the short-term effects, physiological responses, and perceived costs, evidence suggests acceptance to have similar benefits on psychological health. (Troy et al., 2018). Acceptance alters how an individual actively relates to their thoughts or feelings rather than attempting to alter a given experience or emotion (Linehan et al., 2006).

Several research findings suggest emotion-focused coping to be most beneficial when reappraisal is used for immediate evaluation and for individuals experiencing acute depressive or anxiety symptoms and employing acceptance after emotional relief has taken place (Troy et al., 2018; Segal, 2008; Teasdale et al., 2000). Literature also indicates acceptance to be less difficult to use and more effective than reappraisal at altering the physiological response to emotional stimuli (Troy et al., 2018). Though more recent neural imagery shows reappraisal to be more successful at reducing short-term emotional reactivity with greater effort than acceptance (Goldin et al., 2019). Results may vary due to the nature of a study and the individual participants. Thus, additional research is required for determining implications of findings and consistency across literature.

## ACT

Acceptance and Commitment Therapy (ACT) is a mindfulness intervention rooted in empirical science. This “third wave” of behavioral therapy approaches encourages individuals to engage actively and openly with thoughts, feelings, sensations, and memories to create a meaningful life (Hayes et al., 2013). ACT is not driven by avoidance or controlling a given problem but how one relates to their experience. This therapeutic framework finds success in working towards accepting unwanted experiences outside of one’s control and embracing personal values in life. While avoidance may temporarily provide short-term relief, it leads to greater long-term distress and dysfunction (Hayes et al., 2011). As individuals learn to perceive psychological discomfort as harmless and allow anxiety/emotion to fluctuate without judgment, symptom reduction occurs as a byproduct to the transformation process (Moens et al., 2022).

### ***Psychological Flexibility***

ACT is not so much about what an individual is feeling rather than how they relate to it which is explored. Co-developer of ACT, Steven Hayes, labels the ability to “make contact with experience in the present moment fully and without defense” as psychological flexibility (Hayes). When practicing psychological flexibility, individuals can respond with personal values in mind, rather than fighting or avoiding their feelings and thoughts, allowing a healthier relationship with their neural networks and more control over their lives (Aydin & Aydin, 2021; Hayes & Lillis, 2012). There are six interdependent core processes for developing psychological flexibility: cognitive defusion (relating subjectively to thoughts), acceptance, contact with the present moment (focusing on the here and now), the observing self (noticing oneself; Bach et al., 2008), values (an endless component to life, not necessarily something to be achieved), and committed action (adapting behavior in line with values despite ongoing barriers or difficulties; Aydin & Aydin, 2021; Barrett et al., 2019, Hayes et al., 2012). When these processes are practiced continuously and in accordance with one another, psychological flexibility has a positive effect on well-being and decreasement of stress (Wersebe et al., 2018).

### ***ACT and Art Therapy***

Mental and physical illness result in a variety of complex support needs across many aspects of life (Kuluski et al., 2017). Growing empirical evidence supports ACT as an effective treatment approach for a wide range of mental and physical conditions and within numerous therapeutic settings (mental health, primary care, and specialty clinics) and formats (including short workshops, online applications, and telehealth; Dindo et al., 2017). Qualitative and quantitative research continues to support the effectiveness of mindfulness-based art therapy interventions on a variety of diverse populations. Individuals with complex support needs are socially marginalized, and often encounter discrimination and disadvantages as their experiences are bypassed or left unheard (Collings et al., 2017). Art therapy reduces the reliance of verbal communication, allowing an individual to consider their narrative through an active art-making experience. When combined, art therapy can the evidence-based concepts of ACT, creating a genuine, unique, and practical healing transformation for clients (p. 18; Backos, 2022).

Art making engages the mind, body, and spirit. This limits the need for confidently articulating trauma by providing an alternative mode for expressing, understanding, and relating to personal insights and experiences. Visual and symbolic expression welcomes kinesthetic, sensory, perceptual, and symbolic communication (American Art Therapy Association, 2017). Due to the largely non-verbal and bodily experiences of trauma, the mindfulness concepts within ACT show promise in grounding individuals as they recall, work through, and express personal narratives. Though art therapy research is limited, art therapists express direct improvements in cognitive and sensorimotor functions, self-esteem and self-awareness, insight, emotional resilience, strengthening social skills, reducing and resolving conflicts and distress, and in promoting societal and ecological changes with clinical usage (American Art Therapy Association, 2022).

In *ACT Art Therapy: Creative Approaches to Acceptance and Commitment Therapy* (2022), Dr. Amy Backos discusses how the combination of art therapy and ACT is a powerful tool for facilitating social justice. Backos highlights neuropsychological research, emphasizing evidence on how brain plasticity and art therapy can achieve self-regulation (p. 72-73; Carolan & Hill, 2018; Lusebrink & Heinz, 2016; Chapman, 2014; Hinz 2020). Throughout her book (2022), Backos expresses the transformative components of ACT in conjunction with art therapy, highlighting the importance of addressing various contexts in order to best aid clients in internalizing and stimulating change (p. 17). When mindfulness and chosen values are affirmed, individuals can engage in the here and now. Mindfulness in art therapy promotes a nonjudgmental acceptance and release, encouraging patience, trust, gratitude, and generosity (p. 99-101). When ACT research is multilevel, process-based, multidimensional, prosocial, and pragmatic, it promotes cultural humility and growth (p. 241; Hayes et. al, 2021). Though there is still an immense need for unpacking the specific and combined components of art therapy and ACT, this book confirms that striving to integrate the two promotes greater psychological flexibility for all.

## Body Mapping

Mindfulness practices can be found in traditional Eastern philosophical practices as well as Native American tradition (Kabat-Zinn, 2014). Mindfulness improves self-regulation and well-being by connecting mind (awareness and presence) and bodily sensations (Kabat-Zinn, 2014; Mahlo & Windsor, 2021). Reflecting on acknowledging one's state of being can serve as a foundation for deepened self-understanding (Kabat-Zinn, 2014; Mahlo & Windsor, 2021; Schultchen et al., 2019). Body mapping is a mindfulness directive where an individual is instructed to either stand or lay on a paper for an initial body outline. This intervention is a form of externalizing or diffusing trauma, promoting a reclamation of the physical/emotional self through complex processing for increased regulation and growth within the application of art materials (Lusebrink & Hinz, 2016). Following the body tracing, the individual is invited to represent their investigation of self through related visual depictions, symbols, and words (de

Jager et al., 2016). In doing so, body mapping elicits a co-production of knowledge while being a literal and metaphorical approach to storytelling (Gastaldo et al., 2018; Kincheloe, 2001).

Jane Solomon developed the body mapping method in 2002 focused on facilitating knowledge and understanding through therapeutic exploration of life experiences. This project was revolutionary in transforming an art-therapy intervention into a qualitative research tool. Through facilitated therapy for women in South Africa with HIV/AIDS, Solomon's project allowed the women to depict and narrate their experiences through creative art making. Body mapping is done in collaboration between the researcher and participant, combating power imbalances by labeling the participant as an expert in interpretation of preserving the subjective view (Klein & Miller, 2019). This collaboration further works to combat researcher bias while heightening methodological rigor as the participant provides insights and interpretation, leading to a greater sense of gratitude, self-empowerment, and internal validity. For marginalized populations which lack representation in societal-defined narratives (e.g. experience of illness, weaknesses, or stigmatized experiences), the sharing of testimonies ensures the participant's voice is accurately represented (Klein & Miller, 2019). Healing can be attributed within the reconceptualization of narratives where participants depict layered meanings and associations with identity rather than one experience or part being representative of the whole individual (Brett-MacLean, 2009; Skop, 2016).

Internal symptoms and triggers can be overwhelming for individuals with complex trauma (Steele et. al, 2017). Art makes sensory engagement more feasible by providing a container for enhancing somatic awareness and increasing the capacity to focus cognition inward (Davis et. al, 2023). Body mapping serves as a safe approach in capturing a person's complex needs through reflection and embodying visual storytelling which allows the participant to dictate their expression of narrative (Orchard, 2017, p.2). This method engages individuals physically, visually, verbally, and relationally to explore how lived experiences manifest within an individual's body through stored emotion (like how experiences can be stored in memories, embodied knowledge). Additionally, the process stimulates creativity, eliciting a deeper reflection and unveiling of more novel information in relation to social context (de Jager et al., 2016). The healing transformation of these elements emerge through the physical engagement with the artwork, considering and describing the process and meaning of the experience, and relating through conversation and interaction with participating members (Gastaldo et al., 2018; Solomon, 2002).

Top-down processing of traumatic experiences involves verbal responses to sensations whereas bottom-up processing focuses more on the non-verbal aspects within sensory-based responses to stimulus or triggers (King, 2016). Due to the functioning of the limbic system during the originating experience and processing of traumatic events, research suggests "top-down" approaches may not be adequate for expression and healing of trauma (Taylor et. al., 2010). The non-verbal elements to body mapping provide an avenue for bottom-up processing, encouraging participants to tap into disturbing states (e.g., pain, discomfort, and frustration) and connect meaning to the participant's mind, body, feelings, thoughts, experiences and social interactions. This facilitates liberation in experience by establishing and validating the legitimacy of their illness which may have been previously dismissed (Skop, 2016).  The group experience of this data collection validates participants in their sharing of chronic and contested illness disruptions. Additionally, the knowledge each participant brings to the group functions in supporting and inspiring associating members who often feel isolated in their experiences of pain (Bülow, 2004).

Since its creation, body mapping has been implemented as a means for both data collection and therapeutic purposes, applying elements of primarily qualitative research designs. Over time, this form of inquiry has shown to be impactful in community, institutional, and political settings (Gastaldo et al., 2018; Solomon, 2007). Additionally, the combination of narrative, knowledge production, and advocacy strengths within body mapping have been applied to a variety of populations and health concerns. While there is a large range of interpretive strategies across literature, Gastaldo et al. (2018), describe "body mapping storytelling" (BMST), in regard to data generation and analysis, as comparable to what Lincoln and Guba (2013) have labeled as "interpretive critical inquiry" (p.89). With greater understanding and consistent theory, BMST has the potential to significantly transform health research by unveiling diverse and inclusive realities (Sweet et al, 2014). Interpretive critical inquiry acknowledges potential social conflict and marginalization of society and research, to cultivate a detailed understanding of lived experience (Gastaldo et al., 2018).

## Participatory Arts-Based Research

Body mapping is a valuable methodological tool for qualitative inquiry designs, most notably in regard to health research. Literature shows the research use of body mapping to be largely participatory and collaborative in advocating for populations. Though, the benefits of applying specific theory in combination with this research and therapeutic tool have yet to be justifiably explored. Dr. Amy Backos (2022, p. 26) describes the purpose of theory (within therapy) to be crucial in helping clients achieve effective change and understanding of self. The importance of theory is not limited to benefiting a client in therapy. Theory is a motivating framework for researchers to consider direction, structure, expectations, applicable factors, and establishes logical reasoning.

ACT shifts emphasis from symptomology onto personal values similarly to how participatory arts-based research (PAR) favors social justice and critical inquiry over individual problems. PAR designs are effective in unleashing counter-narratives, allowing participants with the lived experiences to be active producers of reflective paradigm shifts. PAR more commonly occurs over a longer duration of time where researchers become part of the community, allowing a detached individual to conduct the determined structure. Thus, integrating ACT theory as a framework for shorter-term studies, such as considering PAR as an influential lens for conducting body mapping research, is promising in addressing aspects of larger social concerns.

### *Decolonising Research and Reflexivity*

Structuring body mapping methodology with ACT theory may also be beneficial for understanding the decoloniality of research projects. Dr. Caroline Lenette (2022) discusses the importance of decolonising methods through cultural safety in participatory arts-based research, acknowledging where she failed to consider cultural safety of the methodology within her own body mapping research (Boydell et. al., 2020). Lenettem, 2022, states reflexivity to be ethically vital for researchers in diverse and complex settings. This refers to understanding bias, awareness, and personal values researchers hold to avoid reinforcing "colonial-ist infused" methodologies." Body mapping originated in Jamaica and South Africa (de Jager et al., 2016). Over time, this participatory method has been adapted and applied to western research contexts. In the process of "whitewashing," some of the originating and culturally safe elements of body mapping have been disregarded through western research applications (Lenettem 2022).

### *Cultural Safety*

Research contributes to decolonization when chosen methodology is evaluated through a culturally safe and reflexive lens (Lenettem, 2022). Purely acknowledging culture within research is not adopting a culturally safe and reflexive lens. Cultural safety recognizes cultural factors (i.e., race, ethnicity, gender, beliefs, moral values, traditions, language, laws, etc.) in relation to the relevant populations' well-being as a means to optimize respect, non-discriminatory agents, and beneficial outcomes (Dawson et. al, 2021). When researchers provide detailed explanations on how they've used methods in culturally safe ways, they are practicing cultural safety (Lenettem, 2022). This does not call for a rigid set of standards or a singular definition of culture but an acknowledgement and understanding of how to consider, integrate, and address cultural perspectives. Thus, arts-based research can serve as a means for researchers to understand the history of chosen methodology, differing contexts of use, and in valuing the participants' lived experiences.

## Film, Advocacy, and Social Media within the Community

If the goal of research is to expand knowledge and deepen understanding of a topic or issue, researchers must also question how this can be done in a culturally safe way. Published academic literature is often bypassed by the general population, calling into question how researchers can best relay information in a way that maximizes the benefits for the population of study. Documentary storytelling through film holds power in increasing emotional connection, encouraging the viewer to relate to a subjects' lived experiences. Additionally, participants can feel valued when agency is given over what they choose to express. Distributing film through various forms of digital media (i.e. social media, new sources, blog posts, etc.), carries the potential for increasing social impact and public interest, generating and contributing to a larger sphere of influence and connection for the population.

When displayed experiences are rooted in factual data and tied to a broader social justice picture, film becomes a methodological approach for initiating public attention, political action, and policy change (Oyalowo et al., 2021). Creative art expression serves as an alternative to traditional forms of printed communication, transforming the way research can be contextualized. In order to strengthen the connection between research and policy, researchers must consider how outcomes of their studies can benefit society (Rogers & Herbert, 2019). Body mapping and documentary filmmaking are collaborative and participatory processes, proven to display narrative context that has previously been bypassed in academia (Lenettem, 2022). While both have been used for institutional and political research communication, ethics and source credibility must also be considered when displaying and advocating with data expressed in documentary film (Oyalowo et al., 2021; Nichols, 2001). For individuals who are yet to be diagnosed with AGS, as stated, increased public awareness may also increase likelihood of a timely diagnosis (Flaherty et al., 2017).

While the combination of collaborative film and arts-based research requires a variety of evaluations to promote data as valid and reliable, film is an accessible resource across a broad range of cultural contexts. Collaborative film holds potential for empowering participants as co-collaborators in expressing personal narrative as a means to connect a lesser known population that has experienced immense levels of societal neglect. Research shows social connection to be essential in lowering chronic illness mortality rates (Tan & Wang, 2019). When individuals feel withdrawn, film can connect them to a community and inspire a prioritization of health. In a world of conflicting information, film can serve as a potential for recentering an individual in the here and now as they absorb content. For individuals who may be feeling overwhelmed in the experience of a chronic diagnosis such as AGS, a documentary film may provide a sense of grounding and direction in beginning to understand the intricacies of daily management. At the very least, a documentary film that captures personal narratives from this population can let those with AGS know there is a community that cares.

# Chapter 3: Methodology

## Hypothesis and Research Questions

The study's research questions include:

1. Do individuals managing Alpha-Gal Syndrome (AGS) express heightened levels of perceived stress?
2. Do individuals with AGS benefit from group participation and art making?
3. Can AGS be associated with food avoidance due to unclear labeling/understanding of the product's manufacturing processes?
4. Will body mapping and/or interviewing reveal a narrative of lived experience for individuals with AGS through emergence of overlapping themes?
5. Will collaborative filmmaking create a sense of purpose and positive inclusion for individuals with AGS?

It is hypothesized that body mapping will work to reveal the narrative of lived experience with overlapping themes for individual participants who engage in art therapy and educational collaborative filmmaking will create a sense of purpose in positive inclusion as measured by intercoder reliability. The researcher predicted elements of Acceptance and Commitment Therapy (ACT) and storytelling to be effective in expressing individual experiences with art therapy serving as a promising tool in connecting participants with AGS through their shared narratives. Additionally, the present study hypothesized individuals managing AGS to report higher levels on PSS-10 and that individuals would find participating in a group to have a positive impact on daily management. Listed below are assumptions about perceived stress and body mapping that were located from literature in art therapy, psychology, philosophy, and neuropsychiatry.

## Mixed-Methods Investigation, Collaborative Methodological Research

The proposed study requested the utilization of a combined quantitative, qualitative, phenomenological art-based inquiry, and collaborative research inquiry. Each component of analysis provided guidelines to achieve an in-depth mixed-methods investigation which validated and privileged the individual experience of participants, labeling them as experts in understanding their own data. When participants assumed this role, they became joint-contributors in the investigation and therefore co-researchers in the collaborative and qualitative research process. The purpose of this study was to explore the experience of individuals living with Alpha-gal Syndrome (AGS) in a way where the results are directly accessible and beneficial towards the population of concern.

This research serves an immense purpose in connecting existing data and management tools while examining both empirical measurements and exploration of dialogue within an interpretive phenomenological framework. Participants exercised autonomy in disclosure of data for a collaborative film representation. The structure of this film serves as an accessible resource and advocacy tool to directly aid, connect, and empower the AGS community in addition to educating viewers on. In completion of this study, this researcher identified currently non-existent psychological and empirical data on this population through first-hand participant expression of experience. The potential outcome of this research holds weight in greatly benefiting and contributing to the needs of individuals living with AGS.

## Definition of Terms

### *ACT Principles/Values*

The criteria for understanding application of ACT principles or Values for data analysis is rooted in the six interdependent core processes for developing psychological flexibility (PF):

cognitive defusion (relating subjectively to thoughts), acceptance, contact with the present moment (focusing on the here and now), the observing self (noticing oneself; Bach et al., 2008), values (an endless component to life, not necessarily something to be achieved), and committed action (adapting behavior in line with values despite ongoing barriers or difficulties; Aydin & Aydin, 2021; Barrett et al., 2019, Hayes et al., 2012). Steven Hayes labels PF as the ability to "make contact with experience in the present moment fully and without defense" as psychological flexibility (Hayes, et. al, 2004). When practicing psychological flexibility, individuals can respond with personal values in mind, rather than fighting or avoiding their feelings and thoughts, allowing a healthier relationship with their neural networks and more control over their lives (Aydin & Aydin, 2021; Hayes & Lillis, 2012). When these processes are practiced continuously and in accordance with one another, psychological flexibility has a positive effect on well-being and a decreasement of stress (Wersebe et al., 2018).

### *Artist and visual art*

The artist is defined by individuals participating in art making (the in-person body mapping session). Visual arts refer to any fine art practices, graffiti, land or environmental art, yet is specific to drawing and film-based disciplines in this study.

### *Art making*

Used in reference for the art creation process.

### *Body Scan*

This is an effective mindfulness meditation practice which roots from Buddhist breathing techniques. The meditation encourages the participant to notice any sensations (thoughts, feelings, physical reactions) without judgment. The intentional breathing and self-connection that occurs within this practice benefits the participating individual through reduced stress and tension.

### ***Body Mapping***

A visual, narrative, and participatory methodology which involves a life-sized tracing on an individual's body. The individual then uses visual art (i.e., drawing symbols, lines, colors, images, etc.) as a means to reflect and articulate complex lived experiences in regard to social considerations.

### ***Collaborative film***

A visual research method in which participants consider, analyze, and respond to specific research prompts. Upon contribution, participants engaged autonomously in disclosing their chosen level of participation to be displayed. Research assistants contributed to the final compiling process in accordance with the study protocol.

### ***Lived Experience***

Personal knowledge, thoughts, feelings, and choices surrounding experiences and decisions. Reflection may take place during the event and/or after. Specific factors may affect a person's understanding and attachment to this (i.e., Age, gender, resources, time spent in the event/situation, etc.). The individual defining the lived experience pertains to their specific first-hand perspective on the situation and how applicable interactions were navigated.

### ***Perceived Stress***

An individual's thoughts or feelings pertaining to the amount of stress they experience at any specific point or over a period of time (Philips, 2013).

## Research Design

In an effort to establish valid context, this research utilized a mixed-method research design. This study required gathering both qualitative and quantitative data in order to best integrate findings and draw inferences in its results. Mixed-methods research has been particularly relevant in providing more in-depth findings for healthcare applications and specifically in identifying complex problems (Hansen et. al, 2016). Quantitative research uses deductive reasoning to generate more accurate and reliable data whereas qualitative research works to reveal in-depth details regarding human experience (i.e., psychosocial factors) through inductive investigation. Each approach holds potential weakness when working in isolation. However, when combined, these processes display strengths in capturing a strengthened and deeper understanding of study results and the concerning population (Regnault et. al, 2018).

Quantitative data was collected through a self-report questionnaire using yes and no questions and Likert-scale responses. This digital survey included the Perceived Stress (PSS-10), a 10-item questionnaire which measures data through five-point Likert-scale responses (0=never, 5=very often). An interpretive phenomenological and art-based research (ABR) method was employed for in-person interviews and art reflections for the intent of prioritizing an understanding of subjective experiences. Phenomenological research seeks to provide details of personal lived experience and art-based inquiry serves as a powerful tool in challenging conventional wisdom by supporting participants in their agency of expression of the explored experience (Leavy, 2023). Morris & Paris (2021) emphasize how ABR methods enhance the translation of research through expanding and eliciting knowledge about lived experience where traditional fieldwork often lacks the capability to effectively do so.

## Participants

Participants for the present study included individuals with AGS in addition to parents of children with AGS. All participants were required to be over the age of eighteen. The virtual survey allowed for participants to disclose if they have been diagnosed with AGS and/or if they are a parent of a child with AGS. All in-person participants (i.e. those participating in interviews or body mapping) were individuals who have been diagnosed with and are currently managing life with AGS. All participants in the study were adults who were comfortable with the level of confidentiality and integration of data into the final film representation. Individuals who participated in person disclosed their comfort and desire to participate in deeper reflections and/or art making as well as to contribute pieces of personal recording to the film. This criterion was included to mitigate discomfort and omission towards the art making and film production processes.

To recruit participants for the study, digital flyers were distributed to social media page administrators and shared electronically across sites, email, and word of mouth. Applicants were recruited through their expressed interest via survey completion and/or direct contact to the researcher. The flier listed the general premise of the study, timeframe, and researcher contact information for interested persons. The researcher contacted interested potential participants via email/phone to discuss the requirements of the study in detail and screen applicant appropriateness for the study by discussing the study items. Individuals participating virtually were not actively screened as applicable study information (embedded into the consent process) was viewed and consented prior to viewing any survey items.

During the initial screening portion of the digital survey and interviews, the researcher addressed potential risk factors and vulnerabilities, time availability, degree of comfort, and level of interest in the project. The researcher also described the study and its requirements, inviting and answering any potential participant questions for clarification. Informed consent forms included consent to participate in the research project and risks and benefits of the study. For in-person measures, informed consent also included film disclosure procedures, digital use of artwork and reflections for publication. These materials were provided and collected virtually and/or in person. Awareness was discussed for sharing of applicable resources (during any point of the study) if participants required additional support. Additionally, it was explained that participants were consenting volunteers with an ability to withdraw themselves from the study or any collected information from assessments, film, artworks, and reflections produced during the study. This could be done for any reason and without need of explanation.

Participant inclusion criteria included: (a) being at least eighteen years old; (b) an individual who manages living with AGS (parents of children with AGS included for survey participation only, individuals with an AGS diagnosis may be considered for all levels of participation) (c) having at least a moderate degree of comfort with personal reflection as evidenced by self-report (d) having a willingness and ability to meet the expectations of the study. Participant exclusion criteria included mental-health vulnerabilities which were screened for upon initial contact and discussion of all items in.  Participants also needed to be able to take precautions in AGS management and agree to applicable safety measures.

## Measures and Interventions

In addition to a clear written description of the research purpose, process, and instructions, virtual participants encountered an 8-item self-report intake questionnaire, the Perceived Stress Scale (PSS-10), and reflective lived experience disclosure (completed in this order). The lived experience section will include 13 items pertaining to health management and a brief writing instruction:

***What is one piece of advice you'd give to someone who is newly diagnosed with AGS?***

Prior to in-person meetings, potential participants will engage in applicable screening assessments for interviews and body mapping. In-person interviews will begin with a body scan meditation in order to maximize participant safety, grounding, mind/body connection, and presence. This meditation will be followed by reflection and verbal and/or written response of nine questions. The provided questions are chosen with integration of motivational and strength-based reflection tools:

1. What do you wish others could understand about living and managing AGS?
2. What is your current relationship to food?
3. What are some things you do to prevent and recover from burnout?
4. Do you feel supported by your family and/or community members?
    a. In what ways does this (if the previous answer is yes) or would this (if the previous answer is no) look like for you?
5. How do you maintain motivation?
6. What is something you wish you knew when you were newly diagnosed?
7. What piece of advice would you share to someone newly diagnosed?
8. How does it feel to know these results will directly help others who are managing AGS?

In addition to the disclosed questions, participants will be provided room to critique and strengthen the study by providing an answer to a self-directed question of choice.

(a) Do you feel there is a question that you wish was asked but was not? If so, please share and we also invite you to provide your answer.

In person body mapping will also begin with a body scan meditation. The art and writing instruction form will prompt artists with the following directions:

(a) Please stand and face the paper, allow yourself to be present in whatever emotion, thoughts, and sensations that may arise as the researcher traces an outline of your body, reminding yourself that you are safe and okay.

(b) After each participant's body tracing is completed, step back to allow a full view of your tracing and consider the following:

    (i) A color to retrace the researcher's drawn outline.

    (ii) To visualize the point on their body where they draw their power, create a personal symbol to represent them, and draw it onto the power point.

    (iii) To create a personal slogan that symbolizes them and their journey with AGS and write it on the map.

    (iv) Draw on areas of the body where they feel they hold physical and/or emotional marking.

    (v) To recall how they found out about their AGS and draw a symbol that represents the issue, printing it as many times as they feel is drawn to repeat it throughout the body.

    (vi) To create a symbol to explain to others what it means for them to live with AGS.

    (vii) To draw their treatment path on the map, including how they look after themselves, their message to the general public, and how they are feeling today.

    (viii) To decorate the rest of their body map until they are satisfied that it represents them.

(c) Now, take several minutes to reflect and represent your emotions, thoughts, and sensations with the provided materials on your designated paper. Color, line, shape, visual, or written expression may be considered. Though, there are no requirements into how you choose to create and display your art nor will you be evaluated on artistic skill.

Once artwork is completed, participants will be invited into discussion and asked to share about their pieces, creation process, reflection, and overall experience. Upon completion of the body mapping session, participants will be invited to consent or withdraw specific public film use of disclosed information, discussion, and artwork. The final film product will be a minimum of ten minutes, no longer than twenty-five minutes.

At the completion of the in-person sessions, all in-person participants were asked to complete a brief written or verbal debriefing evaluation to disclose personal thoughts and/or feelings about engaging in the experience.

## Location

Individuals who completed the digital survey and preliminary screenings were able to do so at the location(s) of their choice. Film interviews were conducted in Raleigh, North Carolina at a rented empty office space obtained through peerspace.com. Artist participants gathered at a rented studio space obtained through peerspace.com. All forms and communication were conducted through alphagal.artherapy@gmail.com and/or via phone and stored in encrypted files.

## Procedures

1. Throughout the entire research process (including the conduction of the literature review, survey collection, development of materials, engagement with participants and artists, their verbal and written expressions, and art submissions, the analysis, the presentation of

the findings, and the development of the discussion and film relating to the findings) the researcher engaged in a mixed-methods investigation, prioritizing the collaboration of participants and expressed narratives. This investigation was guided by layers of participant collaboration. The research involved correlating submitted survey data, experiencing and reflecting upon verbal expression of interviews and the art experimental for disclosed reflections, as well as synthesizing the results of this process and displaying collected data through film. Through these processes the researcher aimed to make currently negated psychological, physical, and perceived context of living with AGS visible and beneficial for the population of study.

2. As the researcher reviewed literature related to AGS, perceived stress, advocacy needs, and the art, prominent and repeated concepts were organized into categories relative to expressed narrative and ACT principles. These categories were chosen through assumptions based on found literature and include perceived stress, management tools, expressed lived experience, cognitive defusion, acceptance, contact with the present moment, the observing self, values, and committed action. Participants were provided additional opportunities to follow-up and reflect and adjust what was disclosed throughout the entire study via email as well as during a designated debriefing session following the completion of in-person interviews and art making sessions.
3. Recruitment of survey participants was conducted via flyers, social media, and word of mouth, requesting interested persons to complete the survey via a shared survey monkey link. Recruitment of in-person interview participants was conducted via flyers, social media, and word of mouth, requesting interested persons to complete the survey monkey link and click the box which states, “I would like to be considered for participating in the

film for an in-person interview" and to provide necessary contact information (i.e. email and phone number). Recruitment of in-person artist participants was conducted via flyers, social media, and word of mouth, requesting interested persons to complete the survey monkey link and click the box which states "I would like to be considered for participating in the film for the two-hour art making and reflection session." Potential participants were also welcomed to contact the student research directly via email at alphagal.artherapy@gmail.com for addressing additional inquiries and/or concerns.

4. Individually, over the phone, through email communication, and digital review, applicants were selected as participants for the study based on their availability, interest, and screening for inclusion and execution criteria.
5. Participants who met the study criteria (this includes completion of the digital survey) were given informed-consent forms on-line or in person and instructed on how to submit the completed forms. Consent was obtained to participate in all elements used for this research including online survey, screening evaluations, in-person context understanding of interviews and body mapping session, use of images and film, and participants ability to determine chosen level of disclosure in the final public film product.
6. Participants were provided with study materials electronically prior to all relevant aspects of research as well as provided a printed out copy of study materials for those meeting in-person prior to participating in the interview process and in-person art making session. This included written instructions for the study.
7. Study materials were collected. Survey data was encrypted and stored digitally, film data was stored in a locked location and only accessed on a secure network. Reflection questionnaires were collected and stored electronically. Physical artwork was kept in a

secure and locked location. Digital images of artwork will be encrypted and stored electronically. All materials were coded for the protection of the participant's identity and kept in an encrypted electronic file.

8. Individuals assisting in any part of the study (i.e., data gathering, data analysis, film production process) were required to sign non-disclosure forms and follow researcher protocol in securing research materials in order to protect the consent and privacy of participants.
9. The researcher bracketed off personal biases, assumptions, and beliefs about the phenomenon of investigation, to remain open and receptive to the participants' lived and expressed experiences to the greatest extent possible.
10. Participants who completed the digital survey submitted self-reported data. Screening questions, expectations, and procedures were addressed prior to in-person protocol and for interviews as well as for the body mapping session.
11. Volunteers participating in the in-person sections began with a researcher-led body scan meditation.

## Materials

- Self-Report Digital Survey
- Self-Report Digital Screening
- Film equipment for Interviews and art making session.
- Interview reflection
- Interview debriefing statement
- White Butcher Paper Roll
- Tape

- 5-7 packages of markers
- Artist reflection statement
- Artist debriefing statement

## Data Collection

Quantitative data was gathered by participant completion of the Self-Report Digital Survey. Qualitative interview data was gathered in four ways: (a) digital screening evaluation, (b) film, (c) participant verbal disclosure, and (d) participant written reflections. Qualitative artist data was collected in five ways: (a) digital screening evaluation, (b) film, (c) participant artwork, (d) participant verbal disclosure, and (e) participant written reflections. In-person participants submitted reflection statements in person or via email.

## Data Analysis

For quantitative measures, percentages were calculated within each survey item (with exception of the PSS questions) and presented from collected survey data, disclosing what percent of individuals selected each answer. The ten questions pertaining to the PSS evaluation were scored for each individual submission. Once all PSS scores were calculated, the results were disclosed in percentages of those who scored low, moderate, or high on the perceived stress scale. The Formal Elements Art Therapy Scale (FEATS) was used by art therapy students to provide blind evaluations on the participant's artwork.

Qualitative results were interpreted through overlapping and correlated themes utilizing interpretive phenomenological and thematic analysis (Smith & Osborn, 2008). The data from separate measures was compared and correlated. Integration of data across measures made it possible to see if qualitative and quantitative data contributed complementary aspects of the same phenomena and helped to develop a greater understanding of the lived experience of individuals with AGS in addition to use of body mapping as a self-reflection tool. A list of themes was compiled and compared with existing ACT principles to determine similarities and differences between the participant's lived experiences of AGS and the artists' will to express and display their narratives through the phenomenon of body mapping.

## Quantitative Analysis

For the Virtual Self-Report Questionnaire, means and standard deviations were computed to assess participants' reports of their perceived stress and Likert scale responses, as well as to locate tendencies and associations within AGS management. The PSS-10 is a valid and reliable stress assessment tool. The PSS-10 displays good concurrent validity (as measured with Cronbach's alpha coefficient and confirmatory factor analysis) and is positively correlated with measures of anxiety and depression. Additionally, the psychometric properties have been translated into a variety of languages with the reliability and validity being verified in multiple countries (Huang et. al, 2020). PSS-10 answers were measured for perceived stress and Self-reported items were analyzed to find quantitative central tendencies and dispersion related to the exploratory questions. Documentation of carrageenan was analyzed based on the percentage of participants who would suffer if the ingredient were to be approved as a processing aid and therefore required for companies to disclose on item packaging. Documentation of group helpfulness was analyzed to display the usefulness of community for AGS management.

## Qualitative Analysis

Phenomenological analysis was used to interpret all the participant written and vocalized statements for qualitative results (Smith & Osborn, 2008). Vocalized statements were transcribed prior to analysis. This form of phenomenological analysis illuminates the descriptive lived experience of the participants. A list of themes was compiled and compared with the discussed

ACT principles of psychological flexibility: cognitive defusion (relating subjectively to thoughts), acceptance, contact with the present moment (focusing on the here and now), the observing self (noticing oneself; Bach & Moran, 2008), values (an endless component to life, not necessarily something to be achieved), and committed action (adapting behavior in line with values despite ongoing barriers or difficulties; Aydin & Aydin, 2021; Barrett et al., 2019, Hayes et al., 2012). This analysis worked to locate similarities and differences between participant's lived experience, suggested advice, and perceptions surrounding the film and art expression processes.

The researcher considered their experience of this investigation and wrote a reflection prior to the analysis, bracketing off their thoughts surrounding the study in order to become aware and eliminate researcher bias as much as possible. The researcher engaged in this process in hopes to also increase their openness to and understanding of the participant's experience throughout each stage. Correlations between the artist's visual representations and disclosed themes were also noted.

Each written response and transcription were read and re-read individually by the researcher as well as a research assistant in order to establish inter-rater reliability with contemplative detachment and openness. The researcher and research assistant(s) highlighted main elements and components of responses including cognitive, emotional, and physical categories. These notes were evaluated by grouping significant and similar condensed items into psychological flexibility categories. The researcher reviewed the bracketed and highlighted elements after inter-rater evaluations and considered how the categorized elements related to each other, making note of commonalities. Subcategories of themes emerged through this process as prominent and common related items and elements were clarified. After the subcategories were developed, the responses were reread to reduce the risk of overlooking disclosed elements. The inter-rater reliability was evaluated based on the consistency of decisions between the researcher and research assistant(s) to aid the project's validity.

## Integration of Qualitative and Quantitative

Self-reported data was coded as quantitative data based on presence (theme code 1) and absence (theme code 2) in evaluation of qualitative themes.

## Protection of Human Participants

All participants were informed and consenting volunteers who agreed to the terms of the project and signed applicable forms prior to research initiation. Participants were provided descriptions of the study, potential risks and benefits in engagement, and instruction for contacting the researcher via email and cell phone throughout the participation period. Specific questions, discomfort, and processing needs will be addressed as disclosed by participants. In the event of sensitive issues arising, participants were appropriately referred to resources and/or available mental health counseling services. The screening procedure assessed safety needs and potential vulnerabilities of potential participants to be excluded from partaking in the study. This researcher followed the ethical guidelines of the American Psychological Association, California Marriage and Family Therapists, California Association for Licensed Professional Clinical Counselors, American Art Therapy Association, as well as the guidelines of the Dominican University of California International Review Board.

Study materials, survey data, and in-person data were encrypted and stored digitally, film data will be stored in a locked location and only accessed on a secure network. Data was encrypted, password-protected, and accessible only to the primary researcher, research study-supervisor, and applicable research assistants. Individuals assisting in any part of the study (i.e.

data gathering, data analysis, film production process) were required to sign non-disclosure forms and follow researcher protocol in securing research materials in order to protect the consent and privacy of participants.

## Confidentiality

Confidentiality was strictly maintained in formal record keeping, no individuals were identifiable within reports and outside of specific participant film disclosure. All participant names remained anonymous and identified by researcher assigned coded numbers. All online surveys, and participant disclosures were coded with a number to match corresponding consent forms. Stored digital data was password encrypted. Unless published or disclosed as part of the public advocacy and education film tool, all information will be destroyed after three years.

## Implications

This potential research shows promise in raising awareness and understanding of lived experience for individuals with AGS while providing powerful insight related to the field of art therapy. The integration of body mapping and empirically proven therapeutic theory may offer insights as to how researchers may consider best practices within art therapy and general research context. Additionally, the present study could directly aid the population of study by providing critical data and context in the form of an accessible and motivating learning tool.

## Limitations

Due to the lack of existing research, time, and resources, in-person results may be limited to individuals with manageable access to the filming locations in Raleigh, NC. This may have limited the ability to gather diverse data across a wide range of economic/income diversity. Additionally, participants under the age of eighteen did not qualify for this study, meaning there is a segment of AGS experience that will be unspoken for. Furthermore, due to the implications of group participation benefiting chronic illness management, data derived from virtual participants may bypass individuals with AGS who are not active members in these groups. Thus, participation in all aspects was limited to those with the ability and means to do so.

Other limitations were revealed throughout the course of the study in relation to potential and listed risks (discussed further in Chapter 5). However, with proper consideration and understanding, these risks were managed and avoided.

### Risks and Benefits

Potential risks to participants included experiencing uncomfortable and unexpected emotional reactions through reflection, discussion, and art creation portions encountered throughout the study. This was influenced by prompted psychological material, study expectations, and/or any life experiences that may have unfolded within the course of participating in the study. Specific risks presented themselves through discussion of trauma and dark themes (i.e. life threatening subject matter), countertransference within group discussions of personal trauma, and the potential for a participant to encounter an allergic reaction while participating in the study (no participant reactions occurred during the in-person sessions). Due to the emphasis on mind/body awareness, and specific body mapping context, individuals with history of body image issues and history of sexual trauma and/or abuse were evaluated as part of the preliminary screening protocol.

In order to minimize potential risks, continual check-ins were provided for in-person participants. In-person participants were asked to refrain from unknown foods/products 48 hours prior to attendance of the body mapping session or interviews, participants will agree to travel with necessary personal emergency medical equipment (i.e., EpiPen, antihistamines, etc.). Locations and contacts of nearby hospitals will be mapped out in case of emergency.

Additionally, all participants were provided helpful tips for recognizing, managing, and communicating about burnout, self-advocacy, mindfulness exercises, and direction in accessing applicable therapy resources. Risks were also minimized by reassuring participants of their autonomy and ability to drop out of the study at any point in addition to appropriate referrals from the researcher. Potential benefits to the participants included: a deepened sense of self-awareness, increased understanding of AGS management resources, expanded access to self-reflection and expression tools, sense of validation, empowerment, accomplishment, hope, connection, and purpose through contribution and completion of the project.

# Chapter 4: Results

Each variable across this mixed-methods study highlights expressed experiences of individuals living with AGS in order to establish a deeper understanding of their shared narratives. In addition to discussing revealed themes, this chapter will provide an overview and present the integrated results from both the quantitative and qualitative measures used to address the following research questions:

1. Do individuals managing Alpha-Gal Syndrome (AGS) express heightened levels of perceived stress?
2. Do individuals with AGS benefit from group participation and art making?
3. Can AGS be associated with food avoidance due to unclear labeling/understanding of a product's manufacturing processes?
4. Will body mapping and/or interviewing reveal a narrative of lived experience for individuals with AGS through the emergence of overlapping themes?
5. Will collaborative filmmaking create a sense of purpose and positive inclusion for individuals with AGS?

## Overview of Development

### *Literature Review*

The variety of aspects touched on in this study is rooted in an extensive literature review as discussed in Chapters I and II of this thesis. The literature focuses on addressing common aspects of AGS management and empirically supported data for the uses of art therapy and body mapping. More specifically, body mapping was reviewed for being an effective processing and advocacy tool for supporting marginalized and underrepresented populations. The evidence-based concepts of ACT guided the structure of this research with the goal of establishing awareness and creating a context for change with a genuine, unique, and practical healing transformation for the involved participants.

### *Quantitative Data*

Quantitative data was evaluated based on documenting, organizing, and calculating recorded survey data. This research took on a latent approach of documenting stated experiences and discussing in chapter five what these statements reveal about the participant's assumptions and larger social contexts. Quantitative data was documented and then used to validate the expressions of qualitative findings by embedding or establishing a relationship between the quantitative survey data and nesting it into the qualitative components.

### *Qualitative Data*

This research began with a deductive approach of confronting the data with some preconceived categories the researcher expected to find reflected in the data. These categories were based on concepts from ACT theory (The Dilemma of Human Suffering, Present-Moment Awareness, Dimensions of Self, Defusion, Acceptance, Values, Committed Action) and an existing knowledge of AGS. Ultimately, this research took on an inductive approach meaning the collected data was used to determine the resulting themes. Qualitative data was understood through thematic analysis beginning with a search for patterns (themes) which capture something significant and/or interesting about the data. Codes were then generated and examined through what fit together into a theme (i.e., Fear is documented as something that encompasses both anxiety). The determined themes of fear (pain, burden), grief (isolation), restriction, confusion, connection, omission, and perseverance, are descriptive of patterns in the data relevant to the research questions and expressed experiences of participants. The organized data was then approached critically in analysis to focus on reporting an assumed reality evident across the datasets.

### *Reflexive Thematic Analysis*

Thematic analysis (TA) was first developed by Virginia Braun and Victoria Clarke in 2006 (Braun & Clarke, 2013). Over the years this approach has evolved to become what is known as Reflexive Thematic Analysis (RTA). This adapted approach is used within a range of theoretical frameworks in order to address differing research question types (i.e., people's experiences, understanding and representation, social processes that influence and shape phenomena, rules and norms that dictate human behavior, people's practices or behaviors, and the construction of meaning) which would require different versions and theoretical frameworks in the traditional model. While there are six defined steps in RTA which build on one another, Braun and Clarke emphasize the value of a flexible and recursive process (movement back and forth between stages) to strengthen the data analysis (University of Auckland, 2023).

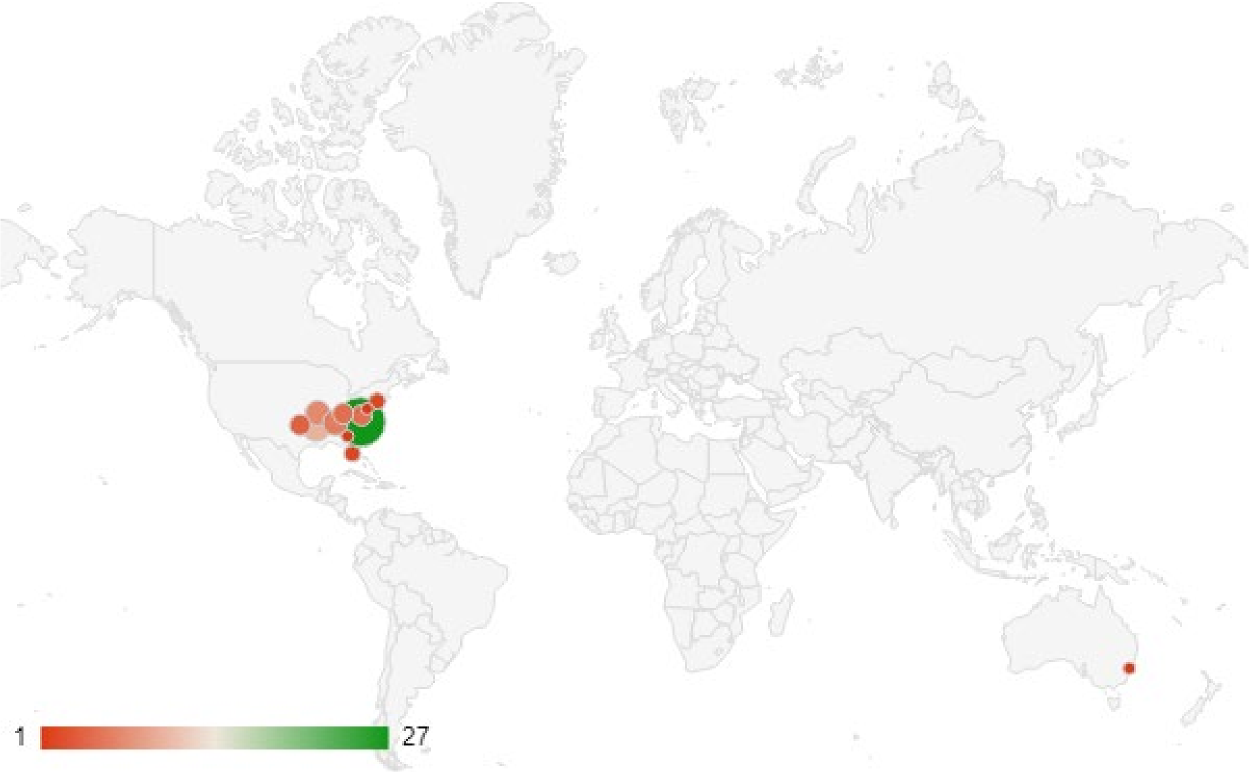
The six phases for analysis include:

1. Familiarizing yourself with the Dataset
2. Coding
3. Generating initial themes
4. Developing and reviewing themes
5. Refining, defining and naming themes
6. Writing up

## Quantitative Data: Survey Results

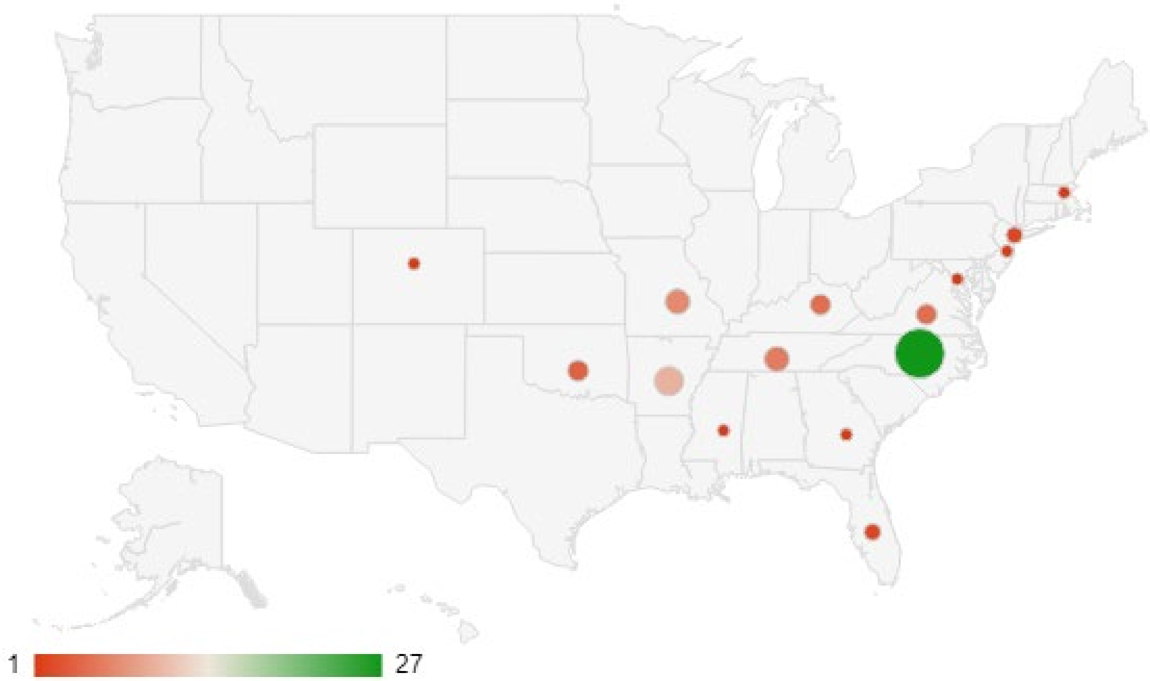
The driving inquiry of this research was to explore the experiences of individuals living with Alpha-gal syndrome. The survey was available and open until completion of this project (three months). During this time individuals within the United States (AR, CO, D.C., FL, GA, KY, MA, MO, MS, NJ, NY, OK, TN, and VA) in addition to an individual from Sydney, Australia submitted their responses. A visual map of these participants is displayed below as Figure 1 and Figure 2. The virtual survey consisted of a series of 31 items. The first seven questions centered around participant demographic characteristics, followed by the PSS-10 (a ten-item measurement empirically used to identify perceived stress), ending with 12 questions focusing on AGS management.

***Figure 1***
*Global Map of Survey Participants*



*Note.* Colored circles display individuals within the United States (AR, CO, D.C., FL, GA, KY, MA, MO, MS, NJ, NY, OK, TN, and VA) in addition to one individual from Sydney, Australia.

*Figure 2*
*Survey Participants Residing in Northern America*



*Note.* Colored circles display individuals within the United States (AR, CO, D.C., FL, GA, KY, MA, MO, MS, NJ, NY, OK, TN, and VA).

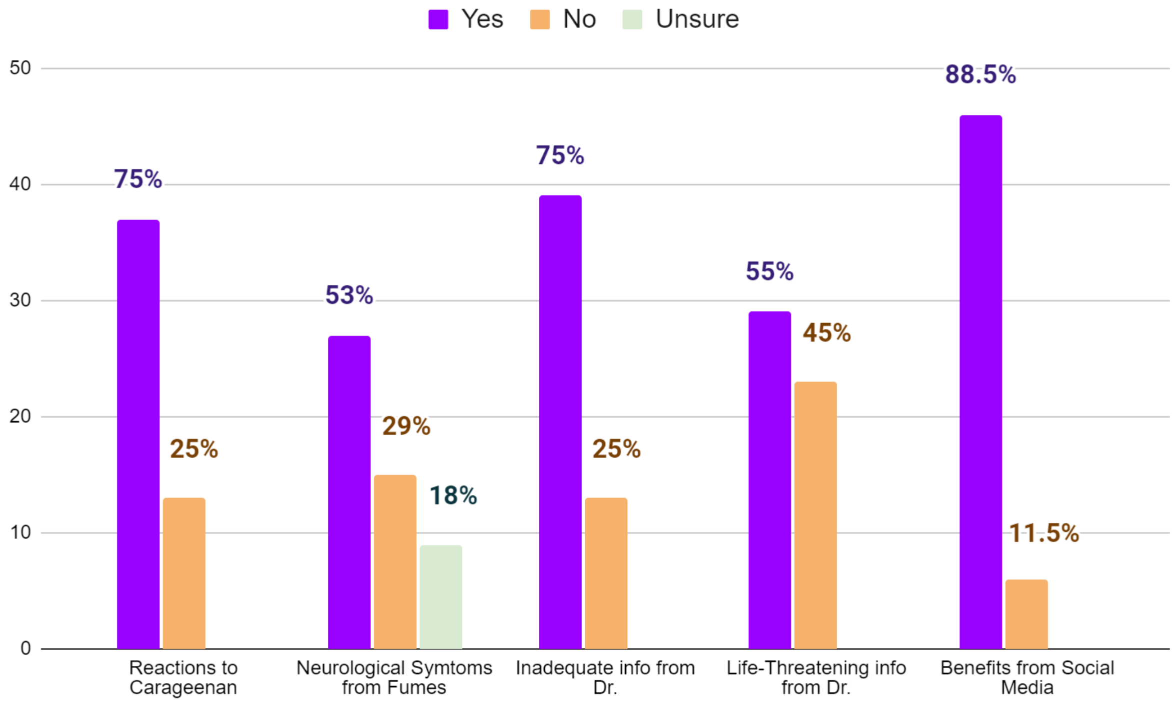
### *Demographics of the Sample*

Fifty one (51) persons completed the survey and of these individuals, (5 males, 47 females), 46 or 86.46% of participants reported being Caucasian. The remaining participants identified as American Indian (one the two further specified as Cherokee), Black, Asian, and Hispanic. Across the completed surveys, participants documented their ages as being anywhere from nineteen to greater than 70 years of age, 38% ranging from 40-49 years, 17.65% ranging from 50-59 years, and 24% ranging from 60-69 years (2 < 29 years, 3 ranging from 30-39 years, 19 ranging from 40-49 years, 9 ranging from 50-59 years, 12 ranging from 60-69 years, and 3 documenting over 70 years of age). Additionally, these participants expressed a broad range of years spent living with AGS (from one month to >40 years). More specifically, 6 participants reported living with AGS for less than one year, 6 participants for 1-2 years, 15 for 2-6 years, 5 for 7-14 years, 1 for 15-20 years, and 2 >20 years. All the results are presented as a sum of the whole rather than individually based on demographic data due to the lack of significance in differentiation of responses across demographics.

The following section displays in figures (Figure 3 and Figure 4) and verbal description the survey questions and the corresponding participant responses.

***Figure 3***

*Management Experience*



*Note:* Reactions to Carrageenan, Neurological Symptoms from Fumes, Life-Threatening information from Doctors, and expressed Benefits from Social Media.

***Has your ingestion of carrageenan resulted in an allergic reaction?***

75% of participants selected “Yes.”

25% of participants selected “No.”

***My spouse/ child/ children, and/or I experience neurological symptoms (difficulty formulating words, forgetting a place in a sentence, brain fog, etc.) after inhalation of fumes which contain the AGS allergen.***

53% of participants selected “Yes.”

29% of participants selected “No.”

18% of participants selected “Unsure.”

***Do you feel you/ your spouse/ your child were not given adequate information regarding AGS from your doctor(s)?***

75% of participants selected “Yes.”

25% of participants selected “No.”

***Have you/ your spouse/ your child or children been given false or harmful information regarding AGS management from your doctor(s)?***

55% of participants selected “Yes.”

45% of participants selected “No.”

***Does Participating in a community group (i.e. Social Media, in-person support, etc.) help your AGS management?***

88.5% of participants selected “Yes.”

11.5% of participants selected “No.”

***How do you and/or your spouse/ child/ children manage Alpha-Gal Reactions?***

In addition to providing several items (i.e., Avoidance, Antihistamines, EpiPen, Benadryl, and Cannabis, this survey question also provided the availability for individuals to write in additional responses. Out of all the submissions:

45 participants selected “Avoidance.”

37 participants selected “Antihistamines.”

35 participants selected “EpiPen.”

12 participants selected “Cannabis.”

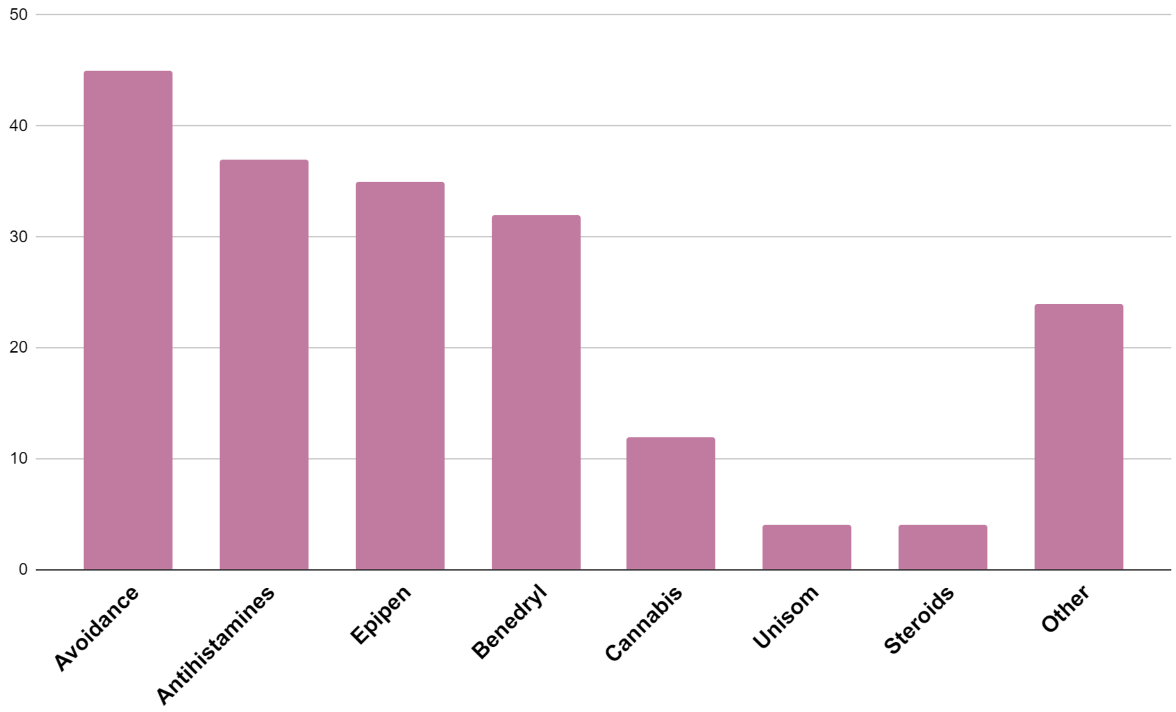
4 participants wrote in “Unisom.”

4 participants wrote in “Steroids.”

24 other management aids were also submitted by a maximum of 3 respondents per item: 2 Quercetin (an antioxidant and natural antihistamine used to treat inflammation), 2 Liquid prednisone (a medication known for combatting arthritic pain), 1 Cannabidiol (CBD), 2 Ibuprofen, 1 Migraine Medication, several asthma medications and mast cell stabilizers (2 Inhaler, 1 Ketotifen, 1 Xolair, and 1 Oral Cromolyn), 3 Pepcid AC (a medication for treating heartburn and digestive concerns), 1 Pepto (a medication used for treating heartburn and nausea), 1 Famotidine (a medication used for treating heartburn and gastrointestinal symptoms), 1 Ativan (a benzodiazepine used for treating anxiety), Water, Sleep, and Mindfulness tools for Stress Management. These results are also depicted below in Figure 4.

***Figure 4***

*Expressed Management Aids for AGS Reactions*

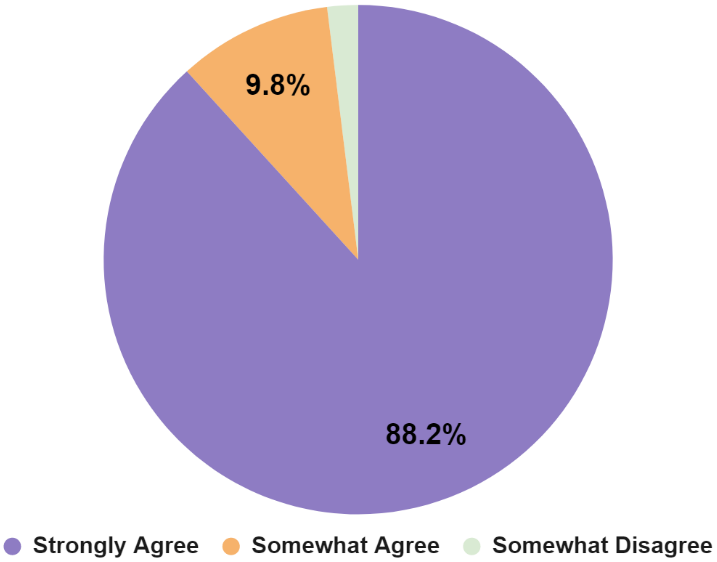


*Note.* Avoidance, Antihistamines, EpiPen, Benadryl, Cannabis, Unisom, Steroids, and Other.

Figures depict the majority of individuals who expressed AGS as being more complex than avoidance of allergen in addition to unclear labeling resulting in AGS reactions, and avoidance of eating, and a poorer relationship to food (Figure 5, Figure 6, and Figure 7) are displayed and further defined below.

**Figure 5**

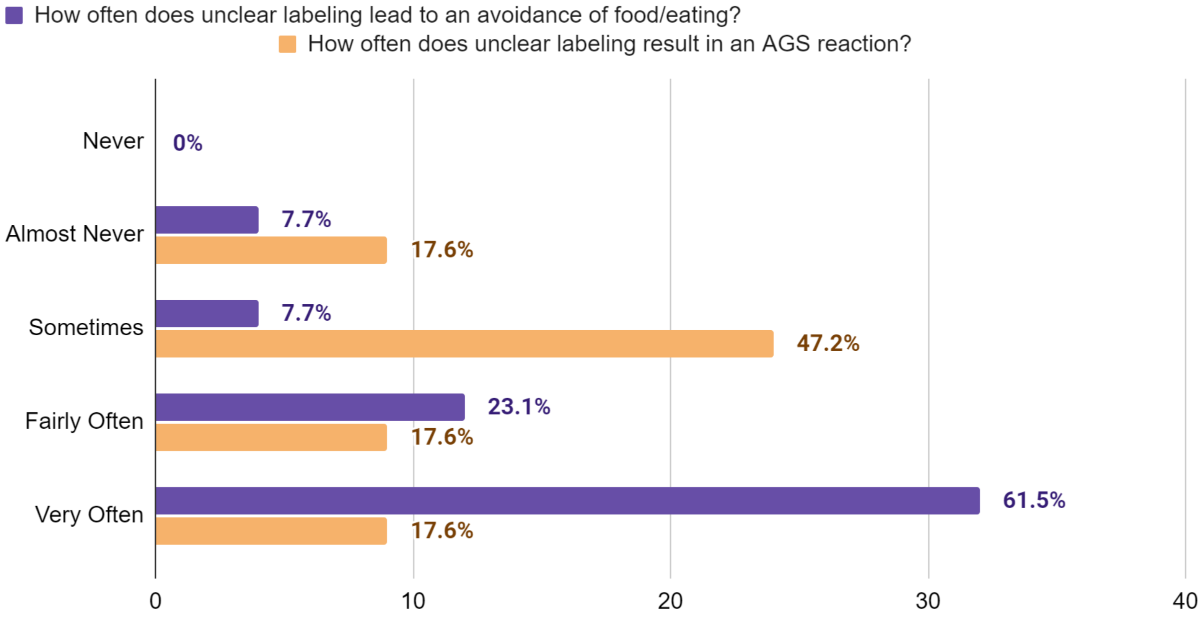
*AGS is not as simple as "Avoiding the Allergen"*



*Note.* 88.2% Strongly Agree, 9.8% Somewhat Agree, 2% Somewhat Disagree, 0% Strongly Disagree that AGS requires more than avoidance.

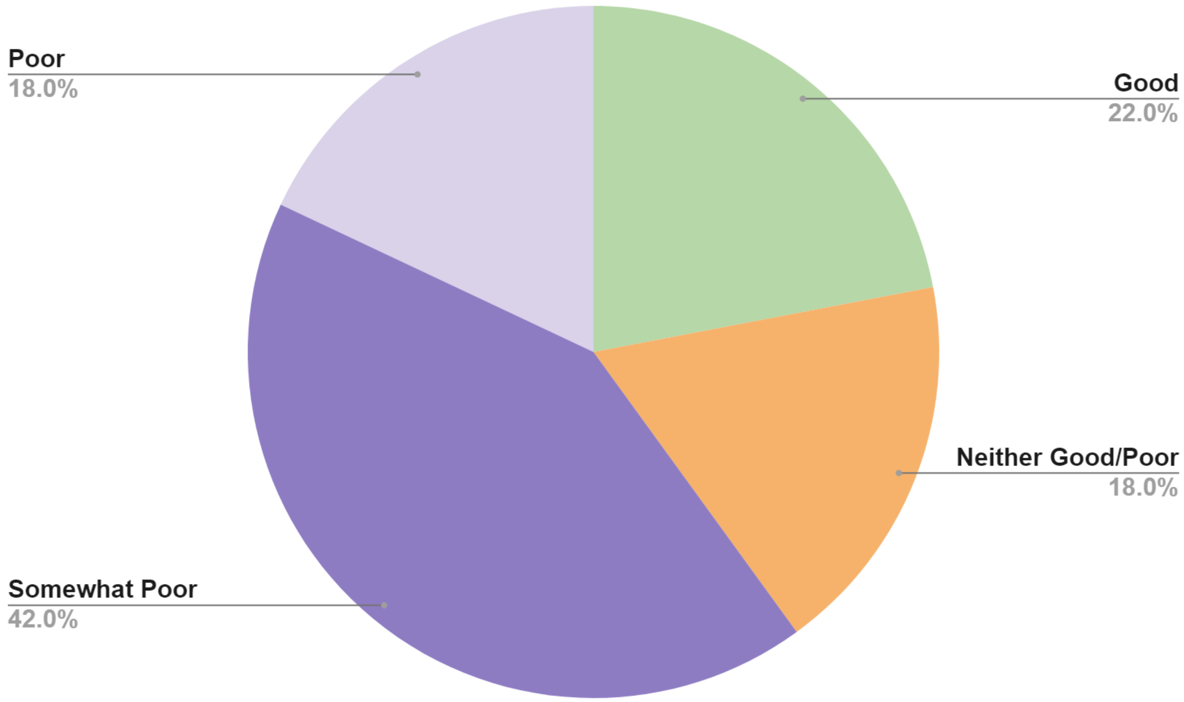
**Figure 6**

*Disordered Eating and AGS Reactions due to Unclear Labeling and Processing*



*Note.* How often unclear labeling/processing results in an AGS reaction and/or an avoidance of food/eating.

***Figure 7***
*Relationship to Food, Regarding Unclear Labeling*



*Note.* 60% reported somewhat poor and poor, 22% Good, 18% disclosed a neutral relationship.

***Living with AGS is not as simple as avoiding the allergen***

88.2% of participants selected "Strongly Agree."

9.8% of participants selected "Somewhat Agree."

2% of participants selected "Somewhat Disagree."

0% of participants selected "Strongly Disagree."

***How often does unclear labeling lead to an avoidance of food/eating?***

61.5% of participants selected "Very Often."

23.1% of participants selected "Fairly Often."

7.7% of participants selected “Sometimes.”

7.7% of participants selected “Almost Never.”

0% of participants selected “Never.”

### *How often does unclear labeling result in an alpha-gal reaction?*

17.6% of participants selected “Very Often.”

17.6% of participants selected “Fairly Often.”

47.2% of participants selected “Sometimes.”

17.6% of participants selected “Almost Never.”

0% of participants selected “Never.”

### *Regarding unclear labeling/processes, what is your relationship to food?*

18% of participants selected “Poor.”

42% of participants selected “Somewhat Poor.”

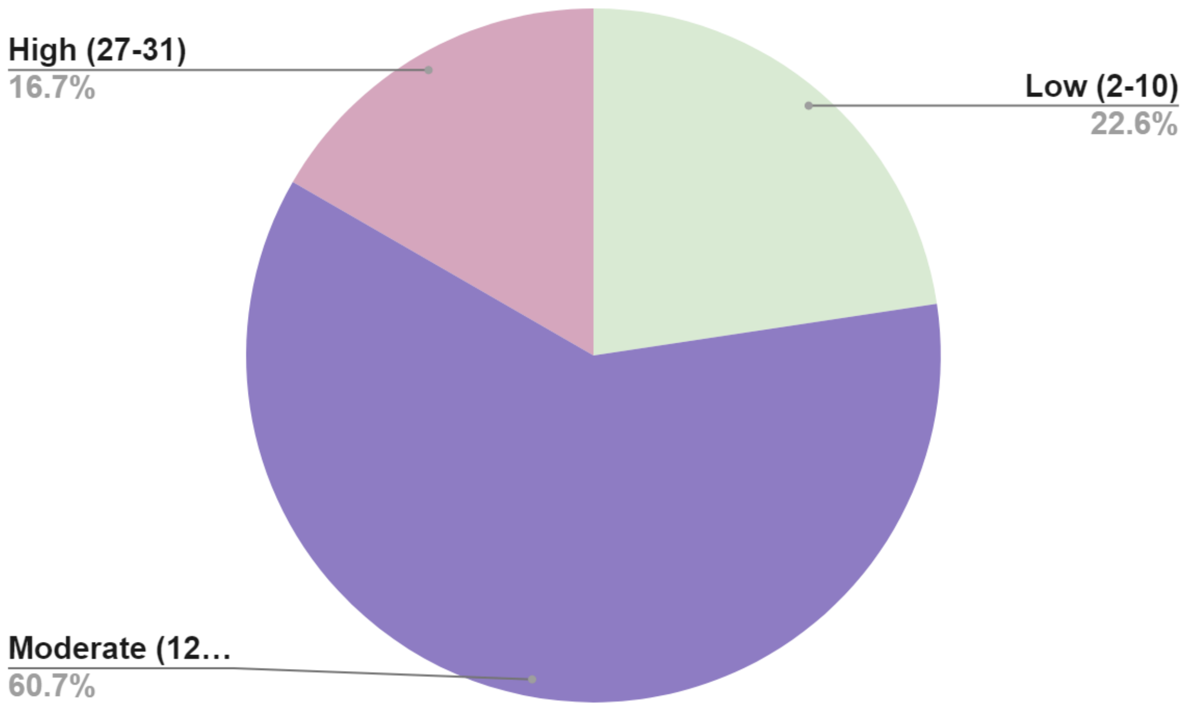
18% of participants selected “Neither Good nor Poor.”

22% of participants selected “Good.”

### *PSS-10 Scores*

Higher scores on the PSS-10 indicate greater perceived stress and the implication of health impacts. Scores can range from 0-40 with 0-13 being low perceived stress and 14-26 considered as moderate. Moderate levels imply frequent worrying about factors outside of one’s control while they attempt to overcome this emotion while low scores can infer the individual’s stress level is not as affected by unpredictable, uncontrollable, and overloaded factors the respondents encounter in their lives. As depicted in Figure 8, 88.3% of participants expressed moderate to high levels of perceived stress.

***Figure 8***
*Perceived Stress Scale (PSS) Scores*



*Note.* Reports of Low, Moderate, and High Perceived Stress.

Within the survey respondents:

16.7% of participants scored High on the PSS (ranging from 27-31).

60.7% of participants scored Moderate on the PSS (ranging from 12-26).

22.6% of participants scored Low on the PSS (ranging 2-10).

### *Mental Health Measurement*

The online survey contained one question asking participants to identify if they/ their spouse/ their child(ren) have AGS and if they have experienced an increase of therapy treatment and/or SSRI dosage since the time of their diagnosis. However, due to formatting limitations within Survey Monkey and time constrictions on modification approval from the International Review Board, the data from this question has been dismissed as unusable.

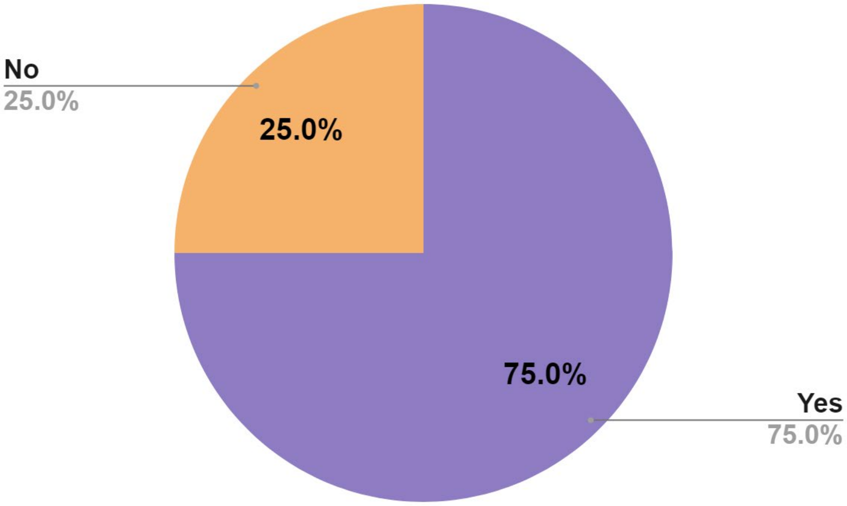
Figure 9 displays the results of individuals who expressed interest in utilizing therapy resources if they were made available. By asking the following question:

***If a therapy resource was available to you, would you use it?***

75% of participants selected "Yes."

25% of participants selected "No."

***Figure 9***
*Individuals with Expressed Interest in Therapy Resources*

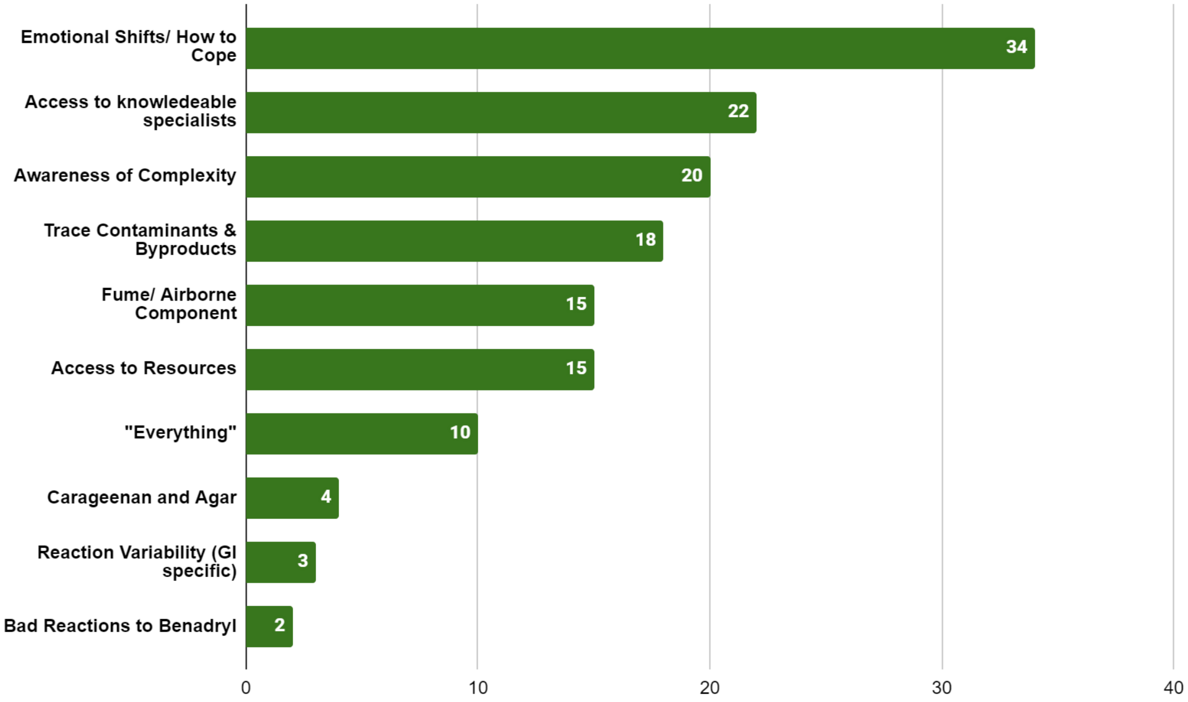


*Note.* 75% who answered "Yes" expressed interest, the remaining 25% who selected "No" stated they would not utilize therapeutic resources.

The final free response item within the survey results allowed for individuals to disclose a statement pertaining to information they wish they knew when they were first diagnosed, as depicted in Figure 10.  Of the 51 individuals who submitted survey responses, a handful of participants reiterated items they had already addressed within the survey questions such as knowledge of: carrageenan (4 participants), fume/airborne reactions (15 participants), and the overall complexity of the illness (20 participants). Other notable items which were submitted in the free response include wishing they knew information pertaining to: the emotional skill set required for coping with AGS (34 participants), access to knowledgeable specialists (22 participants), access to resources (15 participants), the range of variability within gastrointestinal reactions (3 participants), and negative/harmful reactions to Benadryl (2 participants). Lastly, there were 10 participants who wrote they wished they knew "Everything."

***Figure 10***

*What Individuals with they knew when they were first diagnosed with AGS*



*Note.* Emotional Shifts/ How to Cope, Access to knowledgeable specialists, Awareness of Complexity, Trace Contaminants & Byproducts, Fume/ Airborne Component, Access to Resources, "Everything," Carrageenan and Agar, Reaction Variability (GI specific), and Bad Reactions to Benadryl.

### ***Overlapping: Defining and Expanding***

In this study, stage one of qualitative analysis involved watching and re-watching the filmed in-person segments (i.e., becoming familiar with the written response survey data, and qualitative datasets, documenting notes, organizing quantitative data into a spreadsheet, and outlining qualitative structures in order to reduce data into smaller chunks of meaning). This research utilized open coding, meaning there were no pre-set codes. The researcher instead developed and modified codes through the coding process. Initial thoughts pertaining to codes came forward with the completion of step one based on repeated expressions pertaining to the participant's subjective experiences. Stage two was then completed by working through each transcript of text that seemed to be relevant to or specifically addressing the lived experience of individuals with AGS. The next step (stage 3) involved searching for the themes by significance.

This research was driven by the subjective experience of participants which led themes to be coded based on overlap of preliminary themes, characterized by significance. Themes which fit together were organized into broader themes which seemed to say something significant about the research question. The following step (stage 4) involved reviewing themes and modifying and developing them as necessary. In this step, data was considered in association with each theme to establish if the themes worked within the context of the entire dataset (i.e., participant responses across individually expressed virtual and in-person perceptions and across all virtual responses, in-person discussions, and interviews).

Themes were addressed with the following questions:

1. Do the themes make sense?
2. Does the data support the themes?
3. Am I trying to fit too much into a theme?
4. If themes overlap, are they separate themes?
5. Are there themes within themes (subthemes)?
6. Are there other themes within the data?

The final step (stage 5) involved refinement of the themes in effort to 'identify the 'essence' of what each theme is about' (Braun & Clarke, 2006, p. 92). This stage questioned what the theme says in addition to evaluating how subthemes interact and relate to the main theme. The finalized themes found across all study items (i.e., survey data, body mapping, the individual interview, and the community conversation) include the following:

**Physical Alteration.** This refers to expressed change in the sympathetic nervous system response to things which were previously enjoyable (prior to having AGS), also described as a "sense of doom" that can be a common element to anaphylactic reactions.

**Grief.** This refers to expressed disturbance due to loss of independence and ability to travel, loss of comfort foods, behaviors, connection. Other elements encompassed in this theme include isolation, relationship conflicts, and role confusion within the family.

**Fear.** Data placed into this category included expressed fear regarding experiences of physical/emotional pain and anxiety.

**Confusion.** This theme encompassed experiences of confusion due to receiving delayed diagnosis, inadequate information and resources, mislabeling or unclear labeling, and surrounding the participants develop(ed/ing) understanding of AGS.

**Omission.** This theme encompassed experiences of medical/familial/community bypassing, expressed sense of feeling invisible, and scenarios of disbelief.

**Punishment.** This theme included items regarding restriction, shame, feelings of being a burden and the need to protect others, and items relating to job security/punishment in the workplace because of illness induced circumstances).

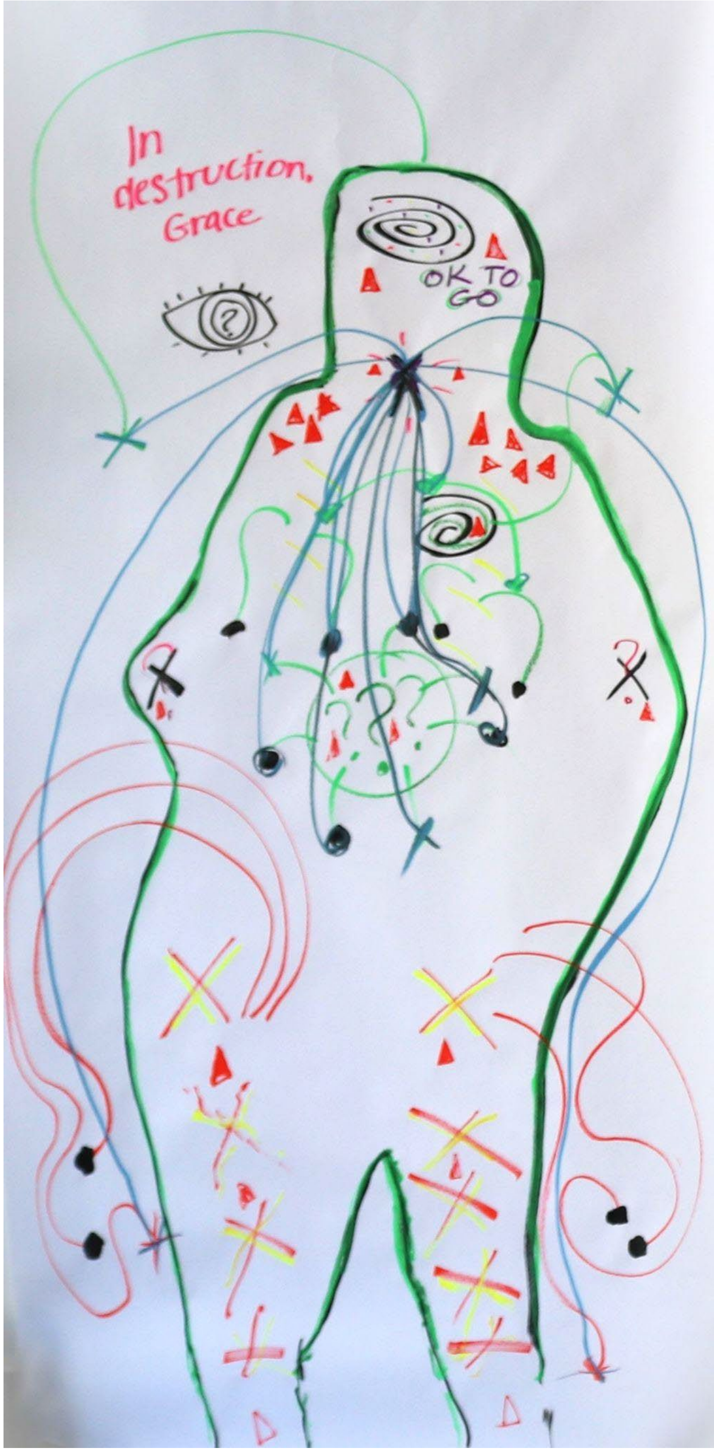
**Perseverance.** This theme encompassed items regarding preservation of self, motivation, advocacy, exhaustion, compassion fatigue, and burnout.

**External Support.** Data within this category were items/expressions of support including connection to community, support, and social media. The documentary serves as representation of these themes.

## Body Mapping

Everyone who completed the virtual survey was asked to submit their potential interest in the two-hour body mapping session and discussion which took place in a privately rented space in Raleigh, North Carolina. Additionally, individuals who contacted the researcher directly with disclosed interest were also considered. Of the 5 available spots, 3 individuals (referred to as P1, P2, and P3) who expressed interest were also able to attend and participate. The produced body maps (Figure 11, Figure 12, and Figure 13) display each participant's symbolically expressed experience of living with AGS in response to the research prompts (discussed in more depth below).

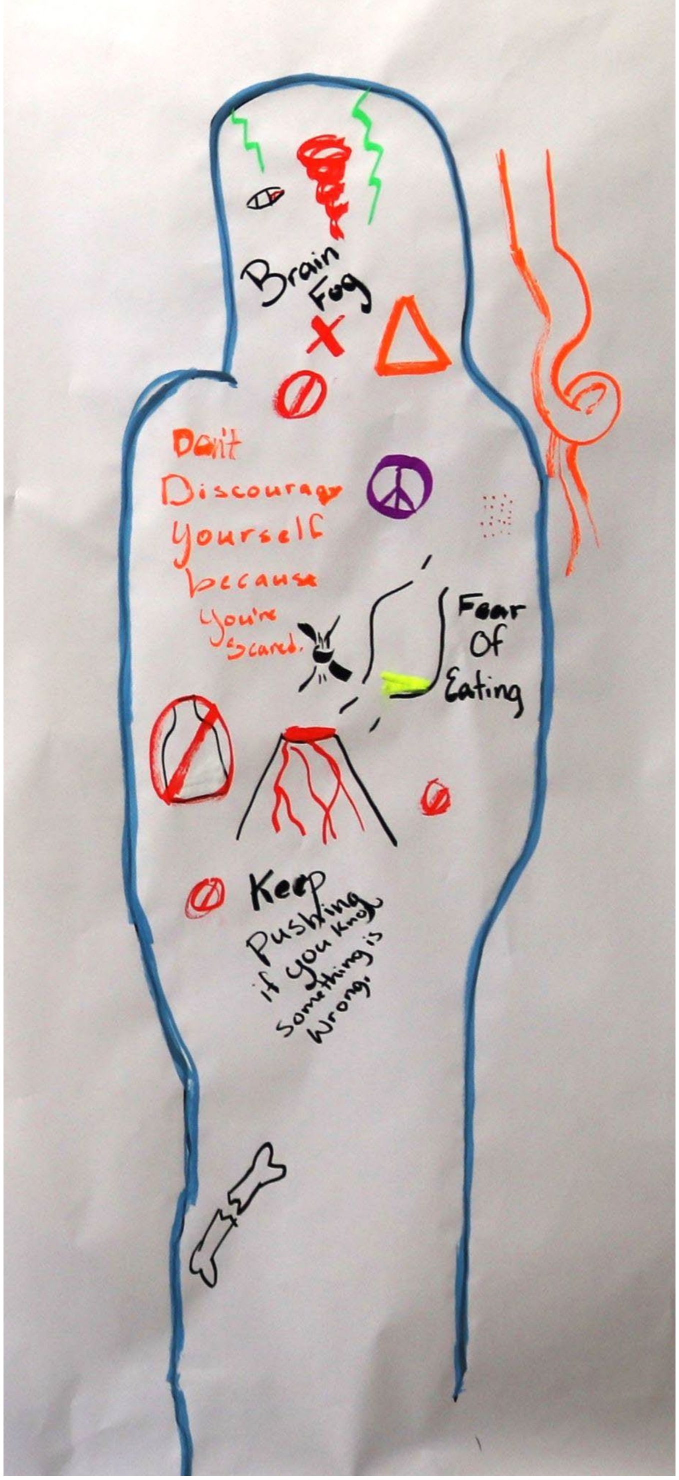
***Figure 11***
*Participant 1's Body Map*



*Note.* 36" x 72" body map drawing on paper with non-toxic jumbo liquid chalk markers.

**Figure 12**

*Participant 2's Body Map*



*Note.* 36" x 72" body map drawing on paper with non-toxic jumbo liquid chalk markers.

**Figure 13**

*Participant 3's Body Map*

*Note.* 36" x 72" body map drawing on paper with non-toxic jumbo liquid chalk markers.

### *Participant 1*

The first participant in this portion of the study is a 49-year old Caucasian female and will be referred to as “P1” for the purpose of this research. P1 has been living with AGS for 2 years and obtained her diagnosis 17 months ago (2022). At the time of this research, P1 also reported being in remission for one month. Remission refers to a diminishing of symptoms which can reappear (relapse) at any given point, not to be confused with a permanent recovery or cure.

### *Participant 2*

The second participant in this portion of the study is a 19-year old Caucasian female and will be referred to as “P2” for the purpose of this research. P2 has been living with AGS for 5 years, after being bitten by a tick while attending public school and confirmed her diagnosis 1 year ago (2022). P2 currently lives with her father and mother who developed an alpha-gal allergy years prior to P2’s exposure. This participant shares a dual relationship with the third participant (P3, documented below) as being an active participant in the body mapping session and the daughter of P3.

### *Participant 3*

The third participant in this portion of the study is a 49-year old Caucasian female and will be referred to as “P3” for the purpose of this research. P3 has been living with AGS for about 15 years, obtaining her diagnosis in 2017 (6 years ago). As mentioned above, P3 shares a dual relationship between P2 as being both an active member of this research and mother to P2.

**Response to Prompts.** After a guided body scan meditation, participants were guided to stand in front of a life size sheet of butcher paper taped to a white wall. Participants verbally agreed on and requested the discussion portion (following the completion of the art making portion) to be structured by walking back through each prompt and allowing everyone to express their creation process and meaning behind the art. However, participants were first asked to consider and create their body maps in response to the prompts in silence. After each outline was traced by the researcher (in a position determined by the participant to represent themselves while facing the paper), participants were each handed a box of non-toxic chalk paint markers as they considered and responded to the following prompts using line, words, color, shapes, and/or symbols:

1. *While facing the paper, determine a position that says something about your life.*
    a. P1 took on an open stance with her left hand placed on her left hip.
    b. P2 took on a neutral stance with her feet placed together.
    c. P3 took on a neutral stance with her feet hip width apart.
2. *Choose a color to trace over your outline.*
    a. P1 chose green, beginning the outline from the top and moving down towards the left side.
    b. P2 chose blue, beginning the outline on the left top side and moving up and over to the right.
    c. P3 chose blue, beginning the outline from the top and moving down towards the left side.
3. *Visualize the point on your body where you draw your power from and draw it onto your power-point.*

  a. P1 depicted a symbol of legs on her throat in purple.
    i. The participant displayed themes of confusion and perseverance by using purple as a color of passion and the symbol being an active one, relating to her persistent feeling/questioning of what action could be made. Specifically stating "I don't know what I can do, but what can I do?"
  b. P2 depicted perseverance by depicting a purple peace sign over her heart, stating "I want everything to be calm and collected, I try to keep things at peace…purple felt peaceful."
  c. P3 also depicted perseverance by depicting a pink heart on the center of her chest and stating, "I try to live life through my heart and do what feels right." When asked about the outlines, P3 verbalized the outlines providing a stronger feeling and pulsing energy of this.

4. *Depict a personal slogan that symbolizes you, and your journey with AGS, and write it on the map.*
  a. P1 wrote "In destruction, grace" to the left of the head in pink. The participant verbalized this in reference to the Goddess Kalima as a reminder that some things need to be destroyed in order to grow and that being "okay." P1 stated this slogan as something she hadn't walked around with but one that was brought forward through the art creation. Themes of physical alteration, grief, fear, confusion, perseverance, and punishment were symbolized in this section. P1 connected this slogan to her struggle between food restriction as a result of AGS and that disturbance challenging her personal experiences/history with disordered eating. P1 stated this element to AGS feeling like a "double punch" which created an

increased "hyperfocus of destruction internally to not focus on food but have to be forced to focus on it" and how that resulted in feeling like there was "no break from the worry."

   b. P2 expressed themes of physical alteration, fear, and perseverance by expressing "Don't Discourage yourself because you're Scared." P2 depicted this inside the body in orange stating there are "A bunch of times where I feel like I shouldn't eat because I am scared of options and the reaction."
   c. P3 wrote "Stay strong. Keep going. Stay safe." This slogan was written in purple and placed to the right of the head. In reflection, P3 expressed themes of perseverance and fear by stating this slogan being "What I wake up and go to bed with. Before, safety didn't seem as big of a concern" and now "every second consists of a worry about basic needs."

5. *Draw on areas of the body where you feel you hold physical and/or emotional marking.*
   a. P1 drew:
      i. Red Xs on the legs and went over these Xs to represent her loss of social connection with food and her loss of community through movement. P1 elaborated and shared this feeling of being left out leading to experiencing grief and fear associated with missing out.
      ii. Red lines over the throat were used to express her allergic responses with feeling like she "couldn't breathe, the constant rash" and experiencing uncertainty in her ability to speak due to reactions.
      iii. A black swirl on the head with multicolored markings as an expression of feeling overwhelmed by medical dialogue. P1 stated confusion through

    sharing her emotion of feeling “like a pioneer in a field you never wanted to be a part of.”

    iv. A green and black swirl over her heart and yellow lines across the chest symbolize physical reactions of pain and inability to breathe while also relating these markings to previously stated expressions of grief.
    v. Black X’s were placed on the elbows, arms, and hands to further emphasize physical reactions and emotional distress. P1 verbalized the X over her hands representing the statement of: “I didn’t know what to do with myself” relating to themes of confusion, grief, punishment, and perseverance.
    vi. Green question marks were placed in a circle in the stomach/gut to symbolize G.I. symptoms specific to AGS reactions and experiences of questioning/fear.
    vii. Through the reflection process, P1 also brought forward a personal experience of fear, punishment, and external support by having her husband sneak her outside to an ambulance to protect her son, stating “I did not want my child to worry.”

b. P2 drew:
    i. A red tornado on the head, surrounded by green lightning bolts, relating these to feeling dizzy/lightheaded with the cracks representing her experience of constant migraines and fear.
    ii. A volcano was drawn in black with red lava to represent how at times it can feel like her stomach is erupting.

    iii. Fear of eating was written in black and represented in a black stomach symbol with yellow marking, relating to physical alteration, grief, fear, and punishment.
    iv. "Brain Fog" was written in black on the head in black.
    v. A black eyeball with red marking was depicted to represent blood shot eyes.

c. P3 drew:
    i. A red exclamation points on the forehead and blue tears as eyes to depict emotional and physical pain (fear) of feeling as though her head is bursting and experiences of migraines, inflammation, and pressure. P3 expressed her reasoning to be "It's hard, and watery eyes are a mild but annoying reaction, but more so that it is hard."
    ii. Orange lines were placed on the neck to represent the feeling of physical constriction (physical alteration).
    iii. A red X was placed over the mouth in addition to one being placed alongside two red exclamation points over the heart to symbolize inflammation and pain (fear). P3 related this placement to "when it affects my heart and lungs, I can't speak or eat" with "can't eat," "can't speak," and "breathe?" written in yellow. Additionally, P3 expressed experiencing increased heart rates as "heart racing" experiences (physical alteration).
    iv. Themes of physical alteration, fear, and perseverance were brought forward through the writing of "Ouch, I'm not okay" on the gut in addition to "pain" being written twice and traced with orange. Other words were

written in yellow including "help, inflammation, pain, fog (referring to brain fog). P3 stated AGS to be "The biggest whirlwind of pain that you can't calm down, you have to wait it out." When asked to elaborate on her choice of bright colors, P1 stated "The bright colors are how it feels inside."

6. *Draw a symbol to represent how you found out about your AGS and repeat this, printing it as many times as you feel drawn to repeat it throughout the body.*
   a. P1 drew red triangles, placing them on the head, shoulders, chest, gut, legs, and neck. P1 expressed themes of omission, and perseverance through the triangles relating to yield signs and "having a lot to carry and do to gain understanding" and "trying to get others to understand that it is not in my mind." P1 expressed specific frustration with this experience of disbelief by her experience of being met with disbelief by doctors despite having the physical lab results stating that her results and expressed experience "were not good enough."
   b. P2 drew a milk jug with a black marker with a red general prohibition sign over it to represent the inability to have things, symbolizing themes of confusion, punishment, and perseverance. P2 went on in dialogue to express her feelings of difficulty in attempting to backtracking and determine what exposure may have triggered a reaction during the day(s) they have occurred.
   c. P3 drew green spirals (beginning at the head, moving to the gut, then to the limbs and chest. P3 expressed these spirals to symbolize fear and the "gut wrenching pain" and "confusion."
7. *Create a symbol to explain to others what it means for you to live with AGS.*

   a. P1 drew a black eyeball with a question mark inside the pupil, symbolizing themes of confusion, omission, and perseverance. P1 expressed the meaning of this symbol through the following statements: “This can be me as I look out, having to question everything, ingredients and little ingredients where triggers can hide,” “This represents people looking back at you with confusion,” and “It has been more in the medical community where I have been met with resistance and it is almost like a resistance of “You don’t know so you must be the problem.” In reflection, P1 also went on to state “Being an advocate for yourself unfortunately is required for AGS.”
   b. P2 drew an orange triangle on her neck and was allowed the ability to refrain from verbal reasoning when stating “Pass.”
   c. P3 symbolized themes of omission by drawing a white face using an X for each eye and a horizontal line for a mouth to the right of the body to express feelings of invisibility. P3 stated her reasoning to be because “They are not interested in learning about it, or they don’t believe you at all. You’re invisible and they don’t believe it is true.”

8. *Draw your treatment path on the map, including how you look after yourself, your message to the general public, and how you are feeling today. Participants were also invited to continue drawing until they felt satisfied with their representations and were encouraged to add anything they may feel was missed by the previous prompts.*
   a. P1 symbolized themes of physical alteration, confusion, omission, and perseverance by drawing green fluid lines connecting various green and blue X’s around and, on the body, red lines around the legs, blue lines connecting the neck

and chest, with additional black X's and dots to represent dead ends. Statements made to express the symbolism of these lines include: "Doctors don't always communicate well with one another and they assume you're just a hypochondriac," "It's Exhausting to advocate for yourself and to live," "I feel like everything is a fight and I lose my ability to fight when I am met with continual disbelief," "Remission is not a cure, it's something that will always be a question whenever any illness comes up," and "The paths are wild…you just have to try to keep making those paths."

b. P2 wrote on the body in black "Keep pushing if you know something is wrong." Additionally, outside of the body P2 drew an orange spiral, verbally stating "It's a windy, curvy path because you think it's going to be okay but then it isn't quite okay. You get an answer but there are trial and error periods even after getting it," and "It's exhausting to advocate for yourself and to live, everything is a fight and sometimes I feel a loss of ability to fight for myself." The themes represented in this section include fear, confusion, and perseverance.
c. P3 depicted themes of grief, fear, confusion, omission, and perseverance. She drew a black stick figure walking across the paper above the head to meet another stick figure with a red heart disclosing "The stick person with the heart is giving love to myself, reminding me to be patient with myself, and looking to offer the same to others." P3 wrote the words "I understand, I am here for you too." P3 shared this stick figure to be a depiction of herself, stating "I'm alone, going about the journey. Researching, knowing there is something wrong but questioning what" in addition to encountering "disbelief from doctors" and being screed for

somatic illnesses, depression, and anxiety. P3 went on to express experiencing anaphylaxis three times and having a separate specialist contact her doctor before being "reluctantly tested and diagnosed." P3 shared her experience stating she "Had to change everything, couldn't visit family or attend cookouts due to fume reactions." P3 further disclosed personal experiences of feeling as though others do not understand the forced change, expressing experiences of grocery shopping leading to being "broken down crying in the aisle" due to the limitations and stating "It is exhausting to advocate for yourself and to live. Everything is a fight and I feel a loss of ability to fight sometimes."

i. P3 closed her discussion of this prompt with themes of external support, stating: "I don't want others to feel alone, even though many of us do. I want others to know that what they feel is valid and real and I'll do what I am able to in order to help people."

**Response to the Experience.** Following the elaboration of prompt depiction, the participants were invited to express any additional thoughts or comments regarding their experience of the body mapping directive. All three expressed feeling challenged in numerous ways:

P1 expressed the directive to be a "good exploration, the art pushed me to think beyond the disease and how it has altered my living and life. There was a deepened self-reflection that happened through the art making." P1 also expressed experiencing a unique relationship with the imagery, stating "The images will stay with me on a visceral level. I now have a visual place to return to when these memories come forward." P1 further stated her new inspiration for seeking out an art therapist to begin working with therapeutically.

P2 stated the experience “Challenged me creatively. I felt it was hard to explain the experience in pictures.” P2 also shared the creative reasoning of “I felt like most of my experience was in body which is why they are in the outline.”

P3 expressed appreciation for the visual representations, while also stating “It felt difficult to relive the traumatic life threatening experiences…It felt like a journey.” P3 also expressed acknowledgement of the symbolism of body map representation by stating “When people see us, they just see how we compose ourselves on the outside, but this is what we are going through on the inside.”

All participants expressed positive comments about the strength they felt was displayed in all three drawings. The three of them also noted appreciation for one another and the “eye opening” art making experience. The three of them acknowledged validation in the experience and understanding that the fear of eating is something they all feel and experience. Further statements of belief were made regarding how there is a lack of access to providers who understand the condition, leading to a large focus on physical symptoms and a neglect of emotional health.

Throughout the discussion all participants nodded their heads in agreement and validation to each verbalization. Additionally, there were several instances where the participants shifted in their seats, had noticeable shaky tones to their voices, and/tears. After noticing signs of discomfort/dysregulation (i.e., apathetic facial expressions, watery eyes, slight shaking and increased tempo in voices and small body movements), the researcher followed up by asking if they felt difficulty in the present moment sitting with any possible flashbacks and memories that were brought up. After each responded with “Yes,” the researcher decided to lead the participants through an additional meditation (not included within the submitted scripts to the IRB.

The script for this meditation is listed below (pausing for 2 breaths between each direction and step):

1. *I invite you to begin by breathing in your nose for 4, hold for 4, release for 4 out of your mouth.*
2. *Think about your body and your experience with your body. Take a moment to thank yourself, your mind, your spirit, physical, emotional. Thank your body for holding that while you acknowledge that you are here, and you are surviving.*
3. *Imagine a colored light of whatever it is you feel you may need in this moment and continue breathing as you feel it begin to fill your entire body.*
4. *Feel this light begin to reach from your head to your toes as it continues to fill you completely, maybe beginning to feel the light pulsing outward against the edges of your body.*
5. *On your next exhale, I invite you to let go of whatever may be causing you any sort of heaviness or distress. Consider breathing out any heaviness or distress. As you inhale, think about letting go of distress and filling yourself with a soothing light in its place.*
6. *Breathing in the soothing color, breathing out to let go.*
7. *Start to bring attention to your toes, awakening your calves. Notice any feelings of grounding in your tailbone. Working up through the fingers…forearms..back… and begin giving your neck a head roll, or moving it gently from side to side.*
8. *On your next inhale, I invite you to stretch your arms above your head.*

9. *And when you're ready, slowly begin to open your eyes as you roll your wrists back down to a comfortable position.*

Following this meditation, participants were also instructed to consider something they could do for themselves after departing as a form of self-care. The researcher further acknowledged the heaviness that could have been brought from unpacking any of the memories during the meeting. Participants were given the opportunity to stay if they desired as well as the ability to speak or write to the researcher in a more private setting.

***Formal Elements Blind Analysis***

Part of the data analysis for the three body map drawings included a blind analysis by four art therapy students at Dominican University of California. These students were provided images of the participant drawings without access to additional study materials (i.e., prompts and data results). Raters were instructed to score each drawing using a modification of The Formal Elements Art Therapy Scale. This scale is used to understand the process of drawing rather than the content of the images, originally a 14 item evaluation. For the purposes of this project the scale has been modified to 6 items, each evaluated on a scale from 0-5:

1. *Prominence of Color*: Evaluating the use and variety of color, 0 meaning color is used only for outlining to 5 meaning color fills as much space as possible.
    a. P1 was rated at 4, 5, 3, and 5.
        i. Average P1 Color Score: 4.25
    b. P2 was rated at 3, 5, 3, and 3.
        i. Average P2 color score: 3.5
    c. P3 was rated at 4, 5, 3, and 4.
        i. Average P3 color score: 4

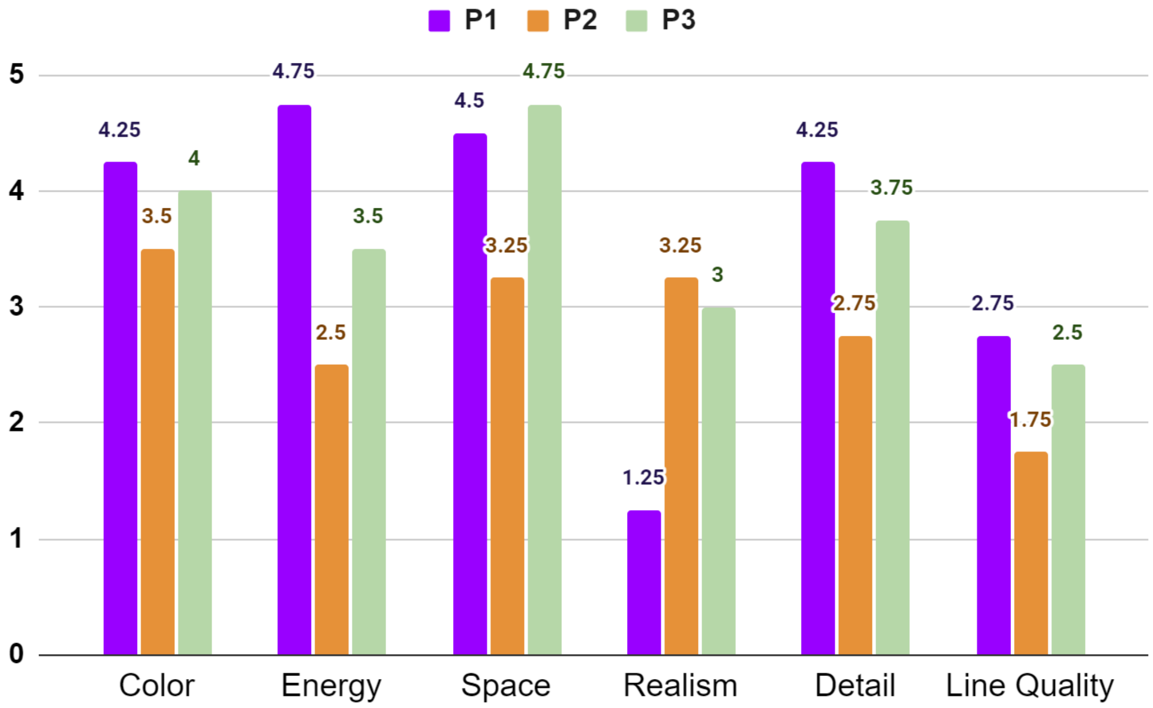
2. *Implied Energy:* Questioning the amount of time the participant took in creating, 0 referring to not very much energy to 5 being an excessive amount.
    a. P1: 5, 5, 4, 5
        i. Average P1 Energy Score: 4.75
    b. P2: 2, 3, 2, 3
        i. Average P2 Energy Score: 2.5
    c. P3: 3, 5, 3, 3
        i. Average P3 Energy Score: 3.5
3. *Space:* Considering how much of the material or percentage of the paper was covered/engaged with, 0 meaning less than 25% to 5 meaning 100% of the space was used.
    a. P1: 4, 5, 4, 5
        i. Average P1 Space Score: 4.5
    b. P2: 2, 4, 3, 4
        i. Average P2 Space Score: 3.25
    c. P3: 3, 4, 4, 4
        i. Average P1 Space Score: 3.75
4. *Realism*: Evaluating how realistic objects and images are depicted in the artwork, 0 being unrealistic to 5 being decently realistic.
    a. P1: 0, 2, 2, 1
        i. Average P1 Realism Score: 1.25
    b. P2: 2, 4, 5, 2
        i. Average P2 Realism Score: 3.25

    c. P3: 1, 5, 3, 3
        i. Average P3 Realism Score: 3

5. *Details of Objects and Environment:* Considering the representation of closer detail and their placement within the artistic image, 0 meaning no details depicted within objects/environment in the image to 5 meaning the image is full of bountiful deltail.
    a. P1: 4, 5, 3, 5
        i. Average P1 Detail Score: 4.25
    b. P2: 2, 5, 2, 2
        i. Average P2 Detail Score: 2.75
    c. P3: 3, 5, 3, 4
        i. Average P3 Detail Score: 3.75
6. *Line Quality*: Scoring the use of lines in the overall image and considering rigid and sharp lines versus fluid and organic lines, 0 meaning broken, damaged lines to 5 meaning fluid and free moving lines.
    a. P1: 3, 0, 4, 4
        i. Average P1 Line Quality Score: 2.75
    b. P2: 0, 1, 3, 3
        i. Average P2 Line Quality Score: 1.75
    c. P3: 3, 1, 3, 3
        i. Average P3 Line Quality Score: 2.5

*Figure 14*

*Modified Formal Elements Art Therapy Scale*



*Note.* Body mapping participant scores of Color, Energy, Space, Realism, Detail, and Line Quality.

**Individual Interview**

Everyone who completed the survey and who had access to the researcher's contact information (email and/or phone) was invited to fill up to ten available slots for individual interviews. However, only one participant was able to participate on this day due to several different time and health constrictions of the few participants who expressed interest. The participant for the individual interview portion of the study is a 55-year old Caucasian female and will be referred to as "P4" for the purpose of this research. P4 has been living with AGS since 1995 (28 years ago) and received a formal diagnosis in 2013 (10 years ago). P4 has four kids aged from 19 to 35 years of age. While this participant has been in remission since 2019, she has refrained from eating any mammal until 2021. After participating in a guided body scan meditation (the same meditation given at the beginning of the body mapping session), P4 was asked the following questions:

1. ***What do you wish others could understand about living and managing AGS?***

   P4 responded with themes of fear, stating:

   *How incredibly scary it is to deal with when you really don't know what is happening and everyone in the medical field says that doesn't make sense, that can't be happening.*

2. ***What is your current relationship to food?***

P4 disclosed themes of preservation of self and punishment through notable behavioral changes in food navigation/relationship while also verbalizing a neutral relationship through her response:

> *Fine now that I am in remission. I am still afraid; I will eat red meat, but I will not eat pork. My brain just has too much of an association with fear and pain, so I won't eat pork…Once I started cooking more (while in remission) and did not experience reactions, I became more and more confident. I just worked my way up in fat and pork was the last thing I tried. But I choose not to eat pork because I am afraid of it.*

3. ***What are some things you do to prevent and recover from burnout?***

P4 expressed perseverance and enjoyment from exploring different recipes while emphasizing the benefits she has received from engaging in exercise, disclosing:

> *Exercise has helped me so much with stress management, depression management, and fear. Exercise has been so much for me.*

4. ***Do you feel supported by your family and/or community members? In what ways does this (if the previous answer is yes) or would this (if the previous answer is no) look like for you?***

P4 expressed themes of physical alteration, grief, omission, perseverance, and external support in the following response:

> *At first, I didn't because I think people thought I was crazy because the medical field just didn't know about alpha-gal. But my children really understood it because they were so afraid, so I felt supported by my family and then my community slowly came on board. I told everyone about it, they thought I was crazy, I didn't care because that is what I was having to live with. I just helped spread the word about it and that helped my community learn. More knowledge is power to me, and I just kept sharing that mantra with everyone.*

5. ***How do you maintain motivation?***

P4 verbalized fear and perseverance by sharing:

> *Once you start feeling better and you're staying away from things you're supposed to stay from. Once you realize what it feels like to feel normal, you want to keep feeling normal. You want to feel what a normal person should be feeling…to avoid feeling anything negative and painful because of how horrible those states feel.*

6. ***What is something you wish you knew when you were newly diagnosed?***

P4 responded with the theme of confusion by acknowledging:

*That alpha-gal is in everything. You have to watch out for everything: toilet paper, deodorant. I had trouble with my shoes and socks from my fabric softener. You just don't realize how much mammal is in everything…I had some probiotics that resulted in hives due to the gelatin capsule being mammal derived…So, I wish I had been more aware of what is encompassed with mammals. Especially make-us. Who would have thought?*

7. ***What piece of advice would you share to someone newly diagnosed?***

P4 answered with themes of perseverance:

*It will get easier; it will get better. But now that you have a diagnosis, you have the power in your hands, you have control. Do not let the disease have control…You have to do what YOU have to do to keep yourself alive and feeling good…Just be empowered and take care of yourself.*

P4 also provided some words of advice for supporting family members, aligning with themes of fear, punishment, confusion, perseverance, and external support:

*Make sure they know that you believe them. And when they are having a reaction avoid thinking "okay, not this again" but if it is a reaction, okay "what can we do to stop it, how can I help you?" opposed to expression frustrations about the limitations and restrictions and blame…You already feel awful, don't make it any worse…Just by being there and knowing they believe you, and that when you're really, really, afraid when you're having a reaction and you have someone beside you that you know, knows how afraid you are and they say "It's going to be okay, I am not going to let you die" because you feel like you're going to die. So just knowing they are with you and they are going to support you and they are not going to let anything happen to you is pretty important.*

8. ***How does it feel to know these results will directly help others who are managing AGS?***

P4 responded with expressions of perseverance and external support stating:

> *I think it is wonderful how this project helps so many people understand their own experiences…It feels good knowing I've helped other people get answers and so this project is really wonderful…This is going to help bring knowledge and awareness that I wish I had when I was diagnosed. It is just really wonderful to share the awareness of it and knowing that it is going to be more understood.*

P4 went on to disclose a personal experience of grief and physical alteration by sharing how AGS had physical alteration to her experience with running:

> *I went from being a jogger of running 6 miles a day to not being able to run and using an inhaler.*

9. ***Do you feel there is a question that you wish was asked but was not? If so, please share and we also invite you to provide your answer to that question.***

P4 highlighted the experience of fear and grief through discussion of fume reactions, stating:

> *That's a scary, scary, thing, to know that if you walk into a grocery store where they could be smoking hams in the back, which is a very common thing in NC, that your blood pressure could just drop, and you could pass out.*

P4 continued to provide another example of the risk of fume reactions affecting her son's life, sharing an experience of fear and punishment:

> *Volunteering at my son's school cafeteria where they were cooking pork led me to passing out while driving with my son in the car. He was 8 years old, and it scared us both so badly.*

P4 also elaborated on the experience of biphasic reactions with the theme of physical alteration by comparing the sensation of her blood pressure dropping to feeling "an oura come over" her.

P4 lastly disclosed themes of physical alteration, confusion, omission, punishment, perseverance, and external support while elaborating on the feeling of being believed, sharing:

> *The feeling of not being believed and then being believed…When you're not believed for so long, after a while it's like oh well, there's no convincing them. At first you feel so frustrated because you know what you're dealing with and you're not making it up and finally I was ready to throw in the towel and think that it was all in my head because of so many people saying "the brain is a very powerful thing." Once it became accepted it was really wonderful when they (medical professionals) would ask me questions and try to learn from my experience. It felt so validating that they wanted to learn from me and they thanked me for helping them understand it. For me, it was so wonderful to know that I was possibly helping the next person that walked into the emergency room.*

## Community Conversation

Twenty individuals submitted an invitation request to respond (RSVP) for the event and ten individuals followed through on their attendance in addition to the three members of the research film-production team. Due to the nature of the community meet-up being open to the public and consent forms being signed at check-in, no demographic data was collected. The meet up was hosted by the researcher (Sylvan Streightiff) and Dr. Jennifer Platt. Dr. Platt received her Doctor of Public Health from University of North Carolina at Chapel Hill in 2013. In addition to her certifications, Dr. Platt has engaged in nearly three decades of work as a researcher and advocate in public, private, domestic, and international policy work. After spending an hour greeting one another and taking time to eat, participants spent the remaining two hours asking Dr. Platt questions and disclosing personal experiences. The themes that came forward (*Physical Alteration, Grief. Fear, Confusion, Omission, Punishment, Perseverance, and External Support)* overlapped with the survey data, body mapping, and individual interview datasets and are further defined in the section below, titled “Overlapping: defining.

While numerous examples were brought forward within the discussion, validating the themes of experience alongside the other datasets. The responses listed below provide examples within each theme:

### ***Physical Alteration***

One participant defined this experience with AGS reactions as a “sense of doom.” This is a change in the sympathetic nervous system response to things which were once enjoyable and is also a symptom which is physically experienced during the allergic response.

### ***Grief***

Countless expressions of grief were made in discussion, expressing a loss of connection, ability to travel, and sense of connection that has resulted in isolating behaviors. One participant specifically addressed their grief over traveling, stating they “no longer feel safe enough to go anywhere.”

### ***Fear***

This theme encompasses experiences of pain and anxiety. One participant expressed fear through “I couldn’t eat anything; I couldn’t go anywhere. I was afraid of everything, and everyone was going to cause me pain or kill me.”

### *Confusion*

This theme was represented through expressions of inadequate information and resources, mislabeling or unclear labeling, delayed diagnosis, and education of AGS. During the conversation this came forward in the required need to question labeling and processing in addition to the actual engagement of meeting up with participants inquiring about AGS questions directly to Dr. Platt.

### *Omission*

This theme addresses the experience of being bypassed, a sense of invisibility from others, and not being believed. An example of this theme came forward when one participant shared their experience of her and her partner working in the medical field and directly witnessing bypassing from other doctors.

### *Punishment*

Experiences were exchanged across participants in this theme of feeling like a burden, specifically within their families with feeling shame associated with the desire to protect loved ones. Several examples were provided with experiences of being punished in the workplace (e.g., being fired) due to the inability to work during an AGS reaction (one of these reactions being triggered at the work site).

### *Perseverance*

Preservation of self, motivation, advocacy, exhaustion, compassion fatigue, and burnout were all expressed by multiple participants. One woman expressed her personal struggle with AGS resulting in other health concerns and being prescribed medications in order to manage all her experienced symptoms. The participant went on to describe the shame and struggle of her preservation of self with this as she has who roots a lot of confidence and pride with identifying as someone who has utilized homeopathic remedies (a form of treating disease or illness with natural substances with the goal of allowing the body to ultimately heal itself) for managing health prior to AGS.

### *External Support*

Everyone who was present expressed their own experience with benefitting from external support such as a greater personal community, supportive family and/or friends, and social media groups. Additionally, the meet-up displayed this theme nonverbally through action of in-person participation.

## Researcher Results

The data represented through the expressed themes (Physical Alteration, Grief, Fear, Confusion, Omission, Punishment, Perseverance, and External Support) were also represented through the produced film. The film itself serves as a reflection of data in an art based form through using these themes as structures for advocacy purposes. Throughout the course of this project (beginning with the initial idea for the project), this researcher kept a journal to document any countertransference and/or personal thoughts. This reflective process data was broken down and understood through the following themes based on the seven ACT clinical processes (expressed below):

### *The Dilemma of Human Suffering*

The researcher documented their motivation for the project being inspired from witnessing and aiding their roommate's (i.e., Sophie/Soph) personal experience with being newly diagnosed with AGS prior to their move to Northern California. Specific journals document her expressing this through the following statements:

- *08/06/2022 - It is hard to be human. It is hard watching my best friend suffer while it is also one of the most inspiring things in my life to be connected to her and witness her navigate such complex experiences. The label of AGS does not begin to address the complexity of this experience. Having a diagnosis seems to mean nothing when it is dismissed. As I sit here and write this, I can immediately recall three other times where Soph has been sent into anaphylaxis from the doctors who are supposed to be helping her. No matter what, it seems as though the pain is always present, we have both just learned to manage and understand it in our own ways.*
- *02/15/2023 - The survey data is heartbreaking. I feel like I knew what the answers would be before reading them, and it feels like all these people have been forced to normalize fear.*

### ***Present-Moment Awareness***

This theme was displayed through expressions of mindfulness:

- *10/02/2022 - I have been sitting in my room for days on end. My back hurts from sitting in this chair, my head hurts from trying to learn to read and understand all these medical papers. I feel anxious, I want to do everyone justice, I want to give credit properly, I don't want to let anyone down.*
- *11/03/2022 - My IRB application was submitted. At this moment, I am filled with joy and pride. If someone were to ask me to share something in my life that I felt proud of, this would be it. I feel meaningful, I feel like I am doing something important. This project is something valuable and, in this moment, I feel a break from the pain.*

- *03/03/2023 - Tomorrow we start our filming so tonight I decided to guide the three of us through some somatic work and an art directive to help ground ourselves in mindfulness while promoting an awareness of how the interactions may affect us. We spent two hours listening to music and walking through the steps, ultimately creating our own scales of presence.*

The drawing on the left represents how the researcher feels when she is ungrounded and dissociated while the image on the right represents the researcher's feelings of presence:

***Figure 15***
*Researcher Scale of Presence*

*Note.* Reflective drawing scale. The left drawing represents the researcher's feelings of dissociation, and the right represents the researcher's feelings of presence.

### ***Dimensions of Self***

This refers to self as context and how framing of language can lead to a sense of self and perspective, sometimes providing a spiritual element within the function of language (i.e., how I versus you, now versus then, and here versus there all influence empathy, theory of mind, sense of self, etc.).

Examples of physical dimensions:

- *09/29/2022 - I was working on my literature review today and I had to stop. I read some data that filled me with tears. I feel nauseated at how many individuals are probably dead because of medical bypassing and how many are left without reasoning because of other marginalizing factors. Every time I feel overwhelmed, I just stop and step outside. Today Soph was with me, so we sat together.*
- *10/10/2022 - I am motivated by this research, it seems as though I just spend every day lately sitting at this desk, isolating myself and connecting myself to the numbers of people I don't know. All I really have done for the past couple months is eat, exercise, sit at my computer, sit with soph, and sleep.*

Example of emotional dimension:

- *03/02/2023 - I'm incredibly anxious and excited to meet everyone in this project. I spent the flight reading over my script numerous times. I feel terrified of the Ticks in North Carolina and probably will not be taking off my repellent infused socks.*
- *03/04/2023 - I messed up. I am feeling a good bit of shame and guilt. I didn't think to check the filtration process on the water bottles I purchased for the group body mapping session, and it turns out that two of the participants experience reactions to this. They brought their own water, but I am afraid my neglectful actions here could have inflicted a sense of shame on all ends.*
- *03/11/2023 - Today at the community meet-up, I felt really validated. Throughout every step of this process, everyone has expressed so much gratitude for it. This gratitude really does evoke a sense of happiness for me. It is difficult not to re-live the pain and fear I have felt with soph when individuals share similar experiences. There seems to be a deal of flashbacks that I am unable to control…*

### ***Defusion***

This refers to how the researcher produces thought in relation to their person. When an element is defused, it is being treated as an item or experience that is externally observed. When an element is fused, it can lead to personal identification, attachment, and/or labeling with the researcher's thought, feelings, and memories rather than remaining as an item that is directly observed.

- *03/04/2023 - I have noticed myself discussing this project as "we" and "us." Soph told me that I need to acknowledge the work I am doing. I guess in ACT terms I have fused myself to the community of this project and just feel as though all this work is everyone's doing. I remember talking about how proud I was of the work I was doing when I submitted my IRB but now, I am having a difficult time acknowledging it as my work because I just feel like it is all of us.*
- *03/29/2023 - Today I caught myself feeling frustrated about my data analysis and telling myself "I suck at math, I don't understand any of this, and I can't do it." Immediately I recognized this was not an absolute but that I am just someone who does not have the mathematical background to easily do correlation calculations. And now, I am just considering if I should attempt to do this or if the energy spent towards figuring it out really means anything. There is just part of me that feels like this data speaks for itself. Then, maybe this is just me trying to convince myself that the world doesn't care about mathematical validity...*

### ***Acceptance***

This theme involves active awareness and acknowledgement of experiences without an attempt to alter their form. Acceptance is not removing the emotion but a way of increasing personal values through action.

- *11/02/2022 - Today I realized I am autistic. Maybe it never came out because my entire life I have dedicated so much effort towards understanding the subtleties of how humans interact. I feel myself grieving slightly for the previous me and I am anxious that maybe this will become a barrier in the research if I am unable to understand and unpack every way it could influence my understanding of self, participants, and the research. At the same time, I am calming myself with this understanding of knowing that this is possibly also my strength. While I can see where it has been a barrier throughout my life…Throughout the course of this research, I see how it has helped me navigate each aspect with incredible detail and organization….I have also seen how I am unable to work or function without these noise canceling headphones at times…I have also seen how difficult it is for me to make eye contact…Filming this research almost seems essential at this point because without it…and the amount of focus I have had to place on eye contact…in addition to wanting to be as present as possible with these participants would be nearly impossible for me.*
- *02/28/2023 - I spent a good bit of time feeling disappointed at my inability to get more culturally diverse samples. There were concerns that flooded my mind of feeling like I did a disservice by further bypassing marginalized communities. I've had to come to a point of accepting that I have put everything I have into this project, I have reached out to so*

*many pages, I have tried. I have to accept that this study cannot address every question and concern, and this can be discussed.*

### ***Values***

This theme refers to items that provide the individual and their life with meaning. Values are not goals; they are guiding factors that influence the choices a person makes and the direction they go.

- *7/10/2023 - I am in a position of privilege. In the past I have experienced so much benefit from connecting with Type-1 Diabetes communities and I feel like because I am in the position of not having to live with AGS that I have this ability to help this community and so I should do the best I can.*
- *03/02/2023 - I want to be as present as possible with everyone I meet and with the experience. I want them to know they matter, and they are being heard. I feel this project is my way of letting people know someone cares.*

### ***Committed Action***

This refers to a sense of integrity that is guided by one's values. Committed action is also acting in service of those values.

- *08/18/2022 - Today soph and I met with Richard. He said that we couldn't do the project together (per program requirements, the two of us would be required to write separate and distinct thesis papers and Sophie had already written half of the paper for her previous project at this point). So, I am still going to do this project, but I don't feel great about writing this paper on my own. That being said, I feel everything is so meaningful and I see so much potential and confidence in my ability to produce something that is* *accessible and beneficial to this population. This is my opportunity to create something that soph didn't have.*

- *04/03/2023 - This project has been met with barriers. I've been challenged in my trust in interpersonal relationships while experiencing an immense amount of trust within the stories and experiences all these strangers have shared with me. I hope this film helps others recognize and accept their situations. I hope this project becomes an example I turn to as I seek to acknowledge my own worth, I am getting it done.*

## Documentary Film as Data Representation

The considerable variety of documentation within this research works to promote a multi-layered approach to research processing and collaboration. The use of documentary film has been utilized in this research as creative data visualization. In this project, the format of the film provides greater opportunity for highlighting the compelling narratives of individuals living with AGS. By providing multiple avenues for visualizing data, this format works to convey messages in a more engaging and accessible manner. Additionally, for individuals with chronic illness, specifically AGS, who are currently still facing prominent bypassing (across personal, medical/clinical, institutional, and societal levels), this film serves as a direct advocacy tool in addressing the very real and severe concerns that come with daily management. The format further connects the population of concern (individuals with AGS) to beneficial resources and communities (as listed in the description of the video) and by connecting this type of visualization to a formal research paper, those who view it can directly access peer-reviewed journals, forcing the viewer to accept the reality of this condition being a very real and life-threatening concern.

Each aspect of this research engages participants, readers/viewers, and the researcher by addressing ACT concepts (The Dilemma of Human Suffering, Present-Moment Awareness, Dimensions of Self, Defusion, Acceptance, Values). Furthermore, the structure of the film mimics the investigative process the researcher took on in order to address the topic of this thesis. The film was produced out of collaborative efforts, beginning with the direct witnessing of the reality of living with AGS through the researcher's support of her roommate.

While the themes associated with the thematic analysis were not determined until the collected data was extensively reviewed, this witnessing led to determining the questions within the virtual survey. The quantitative and qualitative responses (shared through the collaborative collection process of survey participants, body mapping participants, the community conversation participants, and the film observers) all work to further validate the expressed themes of: Physical Alteration, Fear, Confusion, Omission, Punishment, Perseverance, and External Support (proven to be prominent within this research and the narrative of the AGS lived experience). Furthermore, these themes serve to establish structure for the produced documentary.

In addition to potential participant and viewer benefit from the variety of data representation, the film production process serves as a tool for deepening the researcher's role within the project and their understanding/evaluation of the data by being forced to witness and reflect on recorded interactions between themself and the participants. This process also works to deepen the researcher's understanding and application of ACT concepts as each aspect of the research serves as an opportunity to be understood through the theoretical lens as it applies to the AGS narrative. Ultimately, every element contributes to the possible effect of strengthening the psychological flexibility of each person involved in this project (e.g., the participants, the researcher, the audience, and those who are given knowledge about the research through verbalization) through collaborative committed action.

In order to evaluate the effectiveness of these themes coming through, the researcher gathered blind evaluations from six random volunteers who were unattached to the project. Each individual was instructed to view the film and provide two sentences regarding their observation. Afterwards, each individual was asked to evaluate if they felt the themes of Physical Alteration, Fear, Confusion, Omission, Punishment, and Perseverance were addressed (with the ability to go back and rewatch portions of the video). Lastly, each participant was asked to write one sentence on the researcher's role within the project.

### Conclusion of Results

51 participants completed an online survey providing input on a series of 31 items. Of those 51 submissions, the vast majority of individuals with AGS scored moderate to high levels of perceived stress. The quantitative survey results also displayed significance in the majority of participants who confirmed their experiences within the following management related occurrences (i.e. the majority of participants report having experienced this in regards to AGS management): reactions to carrageenan, neurological symptoms following fume exposure of the allergen, receiving inadequate and harmful information from doctors, AGS require more than simple avoidance of the allergen, unclear labeling and processing resulting in an avoidance of food/eating and AGS reactions in addition to a somewhat poor and poor relationship with food, a desire for therapy/therapeutic resources, and a direct management benefit from social media engagement. Of those 51 people, several provided qualitative data in the form of free responses including: a disclosure of management aids and information they would have wanted to know upon the time of their initial diagnosis. Thematic analysis of this data revealed the presence of

seven themes: Physical Alteration, Grief, Fear, Confusion, Omission, Punishment, Perseverance, and External Support.

The seven themes were further identified through body mapping where 3 individuals engaged with researcher-led prompts followed by a group reflection and conversation of their individual creative approaches and symbolic meaning. These seven themes continued to be explored through and the filmed observations. An individual interview allowed one participant to reveal their experience of AGS in response to nine questions. The continued exploration of these themes was also distinguishable through the engagement of the ten participating members of the community conversation where individuals engaged in a shared dialogue pertaining to their experiences living with AGS. The research also included a heuristic evaluation of the researcher's experiences which revealed the reflective process of the researcher to be understood through ACT concepts of: The Dilemma of Human Suffering, Present-Moment Awareness, Dimensions of Self, Defusion, Acceptance, Values, and Committed Action.

Art and theory are examined and explained throughout every chapter of this paper. The final chapter of this thesis (Chapter 5) will discuss the meaning of this research by connecting each aspect of the research through the addressment of the given themes: Physical Alteration, Fear, Confusion, Omission, Punishment, Perseverance, External Support. The concepts of Human Suffering, Present-Moment Awareness, Dimensions of Self, Defusion, Acceptance, Values, and Committed Action within ACT theory will also be addressed through the understanding of implications of this research in the discussion to follow.

# Chapter 5: Discussion

## Introduction

The present study investigated experiences of individuals living with AGS through a mixed-methods approach. Throughout the investigation, the researcher utilized elements of ACT (The Dilemma of Human Suffering, Present-Moment Awareness, Dimensions of Self, Defusion, Acceptance, Values, Committed Action) as a tool for establishing structure in addition to connecting and understanding the participant's expressed narratives. The following research questions were explored and will be further discussed:

1. Do individuals managing Alpha-Gal Syndrome (AGS) express heightened levels of perceived stress?
2. Do individuals with AGS benefit from group participation and art making?
3. Can AGS be associated with food avoidance due to unclear labeling/understanding of the product's manufacturing processes?
4. Will body mapping and/or interviewing reveal a narrative of lived experience for individuals with AGS through emergence of overlapping themes?
5. Will collaborative filmmaking create a sense of purpose and positive inclusion for individuals with AGS?

Quantitative survey data was collected in addition to qualitative in-person art making and discussions (a body mapping session, an individual interview, and a community meet-up/conversation), as displayed in chapter 4. This chapter will connect and discuss the data, expressed needs of this population, and disclosed experiences of individuals living with AGS through an understanding of the themes revealed through the reflexive thematic analysis

(Physical Alteration, Grief, Fear, Confusion, Omission, Punishment, Perseverance, and External Support) and in relation to the initial hypotheses:

- *Body mapping will work to reveal the narrative of lived experience with overlapping themes for individual participants who engage in art therapy*
- *Educational collaborative filmmaking will create a sense of purpose in positive inclusion as measured by intercoder reliability.*
- *The researcher predicts elements of Acceptance and Commitment Therapy (ACT) and storytelling to be effective in expressive individual experiences specifically in regard to art therapy serving as a promising tool in connecting participants with AGS through their expressed narrative.*
- *Individuals managing AGS to report higher levels on PSS-10 and that individuals find participating in a group to have a positive impact on daily management.*

The following chapter will further explore the findings of this study within the context of previous research, limitations, validity, and implications for future research. This chapter will conclude with a reflection of the film and production process, ethical praxis, and reflexivity.

## Results

The central inquiry of this research was to establish a narrative for the lived experience of individuals with AGS. Multiple and complimentary quantitative and qualitative research designs were used to explore and validate the abundance of information disclosed by participants (a quantitative virtual survey, an in-person body mapping, in-person individual interview, and an in-person community conversation). This study revealed consistent and significant results across all data (quantitative and qualitative), establishing AGS to be a life-threatening illness which can require significant alterations in navigating daily life and attempts to prioritize safety.

Additionally, the narrative of living with AGS has been shown to be multi-layered in its effects on the individual throughout the required lifestyle shifts and experience of complex trauma. The collected data further calls into question government regulations in supporting this population through regulation of risks associated with product labeling in addition to expressed needs for access to educational, medical, and psychological resources. Quantitative survey data was collected from fifty-one participants (5 males, 47 females) ranging in age and years living AGS.

While the meaning of these results will be further intertwined in the discussion of revealed themes, the following percentages were calculated from corresponding responses to the survey questions:

- **75%** of participants have experienced an allergic reaction following the ingestion of carrageenan.
- **53%** of participants experience *neurological symptoms* (difficulty formulating words, forgetting a place in a sentence, brain fog, etc.) after inhaling fumes containing the AGS allergen (e.g., cooked or smoked red meat). 18% selected "Unsure."
- **75%** of participants said they were not given adequate information regarding AGS from their doctors.
- **55%** of participants have been provided false or harmful information regarding AGS management from their doctors.
- **98%** of participants expressed living with AGS to be more complex than avoiding the allergen.
- **100%** of participants expressed an avoidance of food/eating due to unclear labeling, 84.6% selecting "Very Often" and "Fairly Often."

- **100%** of participants have experienced an AGS reaction due to unclear labeling, 35.2% disclosing “Very Often” and “Fairly Often,” and 47.2% stating this experience to occur “Sometimes.”
- **60%** of participants expressed a “Poor” and “Somewhat Poor” relationship to food due to unclear labeling and processes.
- **75%** of participants expressed a desire to engage in therapy resources, if made available.
- **77.4%** of participants scored Moderate and High levels of perceived stress.

## Discussion

### *Physical Alteration ANS System*

The theme of physical alteration is defined as a change in the autonomic nervous system (ANS) which is triggered during times of perceived danger (Mulkey & Plessis, 2019). More specifically in regard to AGS, this alteration occurs within the sympathetic (one part of the ANS) nervous system (SNS) response to things which were once enjoyable (the other parts being the parasympathetic nervous system/PSNS which works to restore the body to a calm and composed state and the enteric nervous system/ENS which governs the gastrointestinal tract). Participants shared descriptions of alterations in their enjoyment levels leading to a change in behavior alongside symptoms such as increased heart and breathing rates and shifts in emotional perception. This is a symptom which is also physically experienced during an AGS allergic response and noted by participants as a “sense of doom.” What was being described in these scenarios aligns with the limbic systems (fight, flight, or freeze) response that occurs automatically when a threat is present, pausing nonessential functioning in order to maintain safety for survival.

When trauma is endured, adrenaline and cortisol are released, initiating a sympathetic nervous system response, and essentially shutting down the prefrontal cortex and impairing executive functioning (i.e., decision-making, problem-solving, self-control, reasoning, memory, and other language structures). When the prefrontal cortex shuts off and the limbic system takes over, initial memories of traumatic events become stored in the amygdala to be later triggered and re-experienced (Bari et. al, 2014; Lepage et. al, 2019; Tyng et. al, 2017). Due to the executive functioning impairment, these memories often become fragmented and stimulated through reminders of the trauma. Due to the nature of how physical or sensory input becomes diffused from logical thought at the time of the experience (Kearney & Lanius, 2022), these somatic memories can be triggered and experienced as real threats from anything internal (e.g., thoughts or feelings) or external (e.g., a situation, place, sound, or smell). Thus, the reality of negative associations between previously enjoyed activities for individuals with AGS highlights a very real physiological process of the brain working to protect the individual.

Within the survey, this theme can be easily identified within the fill in response section where individuals were asked to share something they wish they knew when they were first diagnosed. Of the 51 individuals who completed the survey, 34 expressed they would have wished to have been aware of how to cope with the emotional shifts that occur as a result of living with AGS. Body mapping participants illustrated their experience of physical alteration through symbolic mark making and discussing their experience of emotional shifts of enjoyment with activities/behaviors. This expressed experience was further validated across the 3 person individual interview, and the 10 person group conversation, with additional disclosures. Participants expressed a range of scenarios (e.g., exercise, community groups, food, family gatherings, travel, etc.) where they faced a stark shift from enjoyment to fear of experiences that were once perceived as harmless.

Unfortunately, due to the nature of this study and how complex trauma occurs, the expressed emotional shifts also became an active element to individuals participating in the research study. This was a risk listed on signed consent forms as well as a verbalized item stated to each participant by the researcher, ensuring safety and comfortability would be prioritized. As participants opened up about their experiences, they disclosed flashbacks of events, commented on intrusive thoughts and images which came to mind, nightmares, and distress as they recalled experiences of pain, sweating, nausea, trembling, and discomfort. The researcher also observed physical shifts in watery eyes and tearful, shaking/quivering/trembling speech, and body movements (e.g., rocking, fidgeting, tapping, etc.) made by participants as they recalled their experiences. During the body mapping session, one participant verbalized difficulty in feeling as though they were reliving their life-threatening experiences. The struggle to engage with this level of vulnerability was acknowledged and appreciated by the researcher. Additionally, further meditations, check ins, and words of validation were implemented in order to assure healthy levels of regulation and safety for participants prior to departure.

The process of expressing and processing shared experiences works to fuse together the physically stored memories with an understanding and connection to language. The act of creating art also activates the limbic system (Shi et. al, 2017). Thus, when individuals engage in art making, they are simultaneously fusing together physically stored memories and cognitive thought through defusion (e.g., altering the individual's relationship to their thoughts) and processing trauma as a safe and creative observer. Ultimately, the added layer of processing through symbolic and creative expression works to increase the participant’s reflection process and depth of sharing within the discussion. These symbolic and creative processes were validated and disclosed by the body mapping participants through individual statements reflecting on the process, including statements of gratitude for the new and lasting visual language for their experiences of AGS. Additionally, art making has been shown to engage the PSNS, indicating a stimulation of the vagus nerve, promoting healthy stress regulation (as displayed through heart rate variability) and allowing the individual to feel calmer, more compassionate, and clearer (Haiblum-Itskovitch, 2018).

### ***Fear***

Fear is another element to the body's natural safety response and often coincides with anxiety (Beckers et. al, 2023). This theme revealed itself to be central to a large range of each participant's shared experiences. While an individual's fear complex can be protective and healthy, there are also instances where fear becomes a negatively impacting interrupter (Clart et. al, 2015). Over time, an individual can be conditioned by repeated stressors with resulting harmful outcomes (Maren & Holmes, 2015). For individuals with AGS, the experience of fear was central to every aspect of the participant's journey and was witnessed in their responses to fearing the life-threatening and incomparable level of physical and emotional pain and anxiety that one endures from the allergic response. Several participants described this level of pain to be more excruciating than one could describe or imagine without experiencing it.

Fear can interrupt the ability to regulate emotions, impacting how an individual may be able to make decisions and experience emotions. It can further drive our behaviors, attitudes, reactions, and beliefs while leaving us in a state of heightened arousal (Maren & Holmes, 2015). For individuals with AGS, there is no break from this fear. The experience of fear begins as soon as an alteration in the immune system results in AGS allergic reactions without any clear understanding or reasoning as to why. Individuals living with this illness enter a period of what may be perceived as random but chronic reactions to what seems to be nothing. In reality, these individuals undergo a range of symptoms (e.g., hives, burning sensations, lowered blood pressure, watery eyes, neurological impairments, arthritic pain, digestive issues, loss of ability to move/breathe/speak/eat, etc.) all from contamination of an allergen which can be found in everyday home and health products (e.g., laundry detergent, water filters, medications, beauty products, etc.). This experience of intense reactions without cause ignites a fear of everything an individual may encounter within the world around them, including oneself. This fear was validated by 55% of participants who expressed being provided false or harmful information regarding AGS management from their doctors. Ultimately, fear forces a change in navigation of life in hopes to reduce the frequency of the painful experiences of AGS allergic reactions.

Participants expressed a level of relief after receiving their AGS diagnosis. However, this was stated alongside emphasis on the fear remaining present. Obtaining a diagnosis does not remove the threat of exposure. Additionally, avoidance is imperfect as there are countless possibilities for contamination/cross contamination. Each alteration of the ANS, as described above, is driven by the perception and experience of non-verbal and verbal cues of fear. Participants disclosed how these cues can be found through a fear of places, people, activities, unfamiliar products, and food, leading to an experience of distrust of self and others. While this experience of fear was described as an element of AGS which becomes easier to manage over time (as in learning to live with the fear through working to adapt one's environment and risk of encountering possible exposures), it is persistent.

Even the participants in remission disclosed how they believed that their experience of fear will never go away. This was stated explicitly by participating members of the study. In the individual interview, the participant disclosed her continual fear of pork despite being in remission. Within the body mapping session, one participant expressed her remission leading to a confrontation of a new fear of any irregular health symptom being connected to AGS and the possibility of coming out of remission. The most frequently described fear was through the experience of consumption. This fear of eating something which can result in a severe and fatal reaction has led every participant to an experience of avoidance of food/eating (described further below under punishment). The following survey data (as seen mentioned above) validates this aspect to the AGS narrative:

- **100%** of participants expressed an avoidance of food/eating due to unclear labeling, 84.6% selecting “Very Often” and “Fairly Often.”
- **100%** of participants have experienced an AGS reaction due to unclear labeling, 35.2% disclosing “Very Often” and “Fairly Often,” and 47.2% stating this experience to occur “Sometimes.”
- **60%** of participants expressed a “Poor” and “Somewhat Poor” relationship to food due to unclear labeling and processes.

These statistics reveal serious need and concern for further evaluation of AGS food related thoughts and behaviors. Eating Disorders are defined as serious mental health and behavioral conditions characterized by severe disturbances in eating behaviors and related distressing thoughts and emotions (Guatda, 2023). By this definition, the effect of AGS on physical, psychological, and social functioning reveals concern for medically induced disordered eating for individuals living with this illness. Furthermore, the disclosed symptoms surrounding food perceptions and behaviors may also fit the criteria for other specified feeding and eating disorders and/or avoidant restrictive food intake disorder (AFRID; Guatda, 2023). Thus, the element of fear within the AGS narrative is one that is significant and should not be overlooked by medical, clinical, and social support systems.

The body mapping session served as an avenue for participants to confront their fears associated with AGS. One participant wrote the words “Afraid to eat” as she confronted how AGS altered her relationship to food, considering how an experience which used to be joyous and valued with the community transitioned into a fatal concern. As each of the three women reflected on their drawings, they faced their life-threatening events through the creation and deliberation of art making in a safe and controlled space. Confronting these fears resulted in participants reliving aspects of their trauma with dysregulation, pain, and sadness for what they each had endured. Each participant acknowledged their revealed memories while connecting cognitive processing and empathy to the expressed physical and emotional pain. As the three participants emphasized the meaning behind chosen symbols and words, they were able to confront these experiences from a diffused perspective. The images became a new association for their experiences, providing visuals for externalizing their internalized thoughts/emotions/beliefs/behaviors/encounters, resulting in a strengthened sense of connection, validation, empowerment, and healing from the experience (as stated by the woman in conclusion of the discussion).

Through this research, it is clear that the theme of fear is prominent within each aspect of the participants' lives. For these participants, professional medical aid has transitioned from being a reassuring safety net to a fearful and life threatening encounter to be avoided. Participants stated their fears of needing to be treated without the ability of being able to advocate or speak for themselves during the time of a reaction or serious incident. When individuals can speak for themselves, there is also a fear of doctors negating the patient and going against their requested treatment needs. AGS creates a valid fear for common activities such as hiking, backpacking, or at-home gardening. This fear goes beyond tick precaution as numerous instances could occur which require medical aid (e.g., tetanus). For example, if an individual is bitten by a poisonous snake while gardening in their home, they may be taken to the ICU where they are then confronted with the reality of not being able to take any anti-venom medication due to all available treatments containing the AGS allergen.

The reality is that many emergency procedures and medical treatments utilize medications with mammal components or processing. For some procedures and medications, there are no alternative options that are safe for this population (e.g., heparin, birth control, etc.). One participant expressed their experience of doctors assuming AGS symptoms were due to drug use. Had the emergency responders treated her with naloxone, this individual would have died. Fear forces individuals with AGS to critically consider their environments while altering their lives, beliefs, traditions, community, activities, and career paths. While fear may never be fully removed, there is certainly room for improved resources and support within this aspect of AGS for aiding health management and emotional regulation/grounding. Ultimately, routine procedures and medical treatments must be altered for this population. If this alteration does not occur, the resources which are established to aid health will continue to result in an increasing number of AGS related fatalities.

### *Grief*

Grief is central to human functioning and encompasses much more than the death of a loved one (Fernández-Alcántara et. al, 2021). At the root, grief is an experience of loss and has been noted in this study through the loss of abilities and experiences individuals with AGS have experienced as a result of living with the illness. This includes loss of culture, connection, ability to travel, independence, control over the physical and emotional self, and the resulting isolating behaviors. As mentioned previously in the literature review chapter of this paper, prolonged and significant levels of grief can disrupt immune system functioning and be associated with self-neglect and suicidal thoughts (Szuhany et. al, 2021). Participants expressed grief in terms of psychological distress, separation anxiety, confusion, yearning, obsessive dwelling on the past, and apprehension about the future.

The stages of grief (denial, anger, bargaining, depression, and acceptance) are not bound to one order (Stroebe et. al, 2017). The individuals participating in this study disclosed their feelings of shock, numbness, confusion, shutting down, frustration, impatience, resentment, embarrassment, range, loss of control, guilt shame, blame, fear, anxiety, insecurity, sadness, despair, helplessness, hopelessness, disappointment, and being overwhelmed with great vulnerability and authenticity in to be experienced as an infinite loop of grief with a unique experience of acceptance. For individuals with AGS, the act of acceptance appears to be a more commonly forced cognitive and logical process rather than an empowering felt sense or belief (e.g., self-compassion, feeling validated, being present in the moment, coping healthfully, etc.) as it was most frequently paired with negatively intrusive emotions and thoughts (e.g., helplessness, resentment, shame, fear, blame, frustration, numbness, feeling out of control).

Individuals with AGS have an unwanted identity thrust upon them, forcing a level of acceptance of this new reality in order to move forward (due to the risk of denial resulting in life-threatening consequences). Participants expressed this experience alongside the emotions of grief in relation to confronting their identity where AGS resulted in questioning their identity and the role they felt they played. The element of role and identity grief was shared through examples of children taking on parental roles, the inability to cook or participate in cultural traditions and social gatherings, or the inability to continue working in specific careers and hobbies and/or passions. Grief over self brings into question what constitutes identity/reforming identity, how individuals with AGS cope and restructure an understanding of self with this, and how the element of fear may affect and prolong periods of grief for this population.

Body mapping encouraged participants to directly confront altered identities through creative processing and healing. Participants acknowledged and expressed their losses on their maps while processing and sharing how they responded to this AGS element. This brought forward feelings of sadness, remorse, frustration, helplessness. Additionally, the women acknowledged their individual needs to accept forced and abrupt loss as an aspect to their realities in order to maintain inspiration, motivation, and empowerment for moving forward from disturbances. The art provided visual storytelling and embodiment of this process through connection and verbal expression of this theme. Confronting their images allowed the participants to reflect on a rendered collection of loss and gain a sense of appreciation for their strengths in what had been endured.

### ***Confusion***

This theme addresses participant concerns for and attempts to address a need for access to adequate information, resources, clear labeling, and medical/clinical understanding of AGS. The experience of confusion, associated as a predominantly frustrating or helpless state, was paired with experiences of fear and anxiety. Participants expressed confronting confusion in physical, emotional, internal, and external scenarios. For individuals with AGS, confusion signifies a desire to understand or attempt to gain a sense of control through understanding an illness which is far more complicated than what one experiences with traditional allergies. When AGS floods the individual with fear and anxiety, resulting in an abundance of input, change, and decisions to make. Body mapping imagery displayed this through participant reflections of their expressing their journey with AGS. Each participant drew symbols/words/images, ranging in fluidity to rigid and abstract to realistic or literal depictions to display (and verbally interpret) these expressed aspects.

**98%** of survey participants expressed living with AGS to be more complex than avoiding the allergen. This statistic was further validated by every in-person participant through the sharing of their lived experiences. Participants' reflections revealed confusion to be associated with accessing information, resources, and knowledgeable medical professionals in addition to the frustration associated with inadequate labeling for product ingredients and processing (to be discussed further below). Due to the range of symptoms, there is no exact blueprint for determining consistency in severity of reactivity across all ingredients or products containing the allergen without individual trial and error periods (e.g., it is possible an individual may be reactive to dairy yet still tolerate consumption of lower fat cheeses such as feta cheese or cheese containing vegetable rennet and no added vitamin D or gelatin). Ultimately, the theme of confusion revealed itself to contribute to individuals with AGS feeling lost and helpless in the process of managing their lives, furthering the risk for disbelief, self-bypassing, and heightened anxiety.

Confusion was also expressed through the need to backtrack possible exposures/triggers (due to the delayed response), and the physical experience of neurological impairments which individuals endure as a result of reactions. Survey data revealed **53%** of participants experience *neurological symptoms* (difficulty formulating words, forgetting a place in a sentence, brain fog, etc.) after inhaling fumes containing the AGS allergen (e.g., cooked or smoked red meat). 18% selected “Unsure.” While this statistic connects neurological decline as a result of fume exposure, brain fog (characterized by confusion, forgetfulness, and a lack of focus and mental clarity) was disclosed to be a symptom persistent across all participant exposures.

The experience of confusion complicates AGS management by disrupting one's ability to live independently and fulfill self-advocacy needs. As stated earlier: **75%** of survey participants expressed they were not given adequate information regarding AGS from their doctors and **55%** of disclosed doctors providing false or harmful information regarding AGS management. These statistics were emphasized by participants with disclosures of how doctors provided a diagnosis with the only instruction for management being to “avoid eating red meat.” This does not signify all medical professionals or specialists to be inadequate in serving AGS patient needs. These statements serve to highlight how access to correct and beneficial information/resources can be the difference between life and death in this illness while lack of access may lead to an increasement of distrust, fear, anxiety, and resulting isolating behaviors. Addressing the theme of confusion in its entirety infers a great need to expand knowledge within the professional sphere in order to minimize levels of confusion and possible resulting distrust/fear for individuals with AGS, as emphasized and desired by the study participants.

### ***Omission***

This theme encompasses the experience of being bypassed, a feeling invisible in the eyes of others, and not being believed. AGS is an abnormal illness which defies previously established understandings of immune system functioning regarding allergies. While actions are continuing to be taken for increasing awareness and knowledge of AGS, there remains a level of resistance to accepting this reality. As participants shared their journeys in navigating AGS, they expressed similar narratives in being bypassed by doctors or loved ones, often dismissed and referred to psychiatric departments for incorrect diagnosis. Several participants also disclosed their experience of being dismissed by specialists despite obtaining test results to prove their AGS diagnosis, impeding their ability to access critically needed medications such as an epipen. Within the body mapping data, this was symbolized through an invisible face alongside expressions of disbelief, deepening the context for this experience with associated emotions and memories they attributed to the theme.

When being bypassed, dismissed, or not being believed is experienced at the hands of medical professionals, it can lead to increasing amounts of self-doubt and self-bypassing where individuals with AGS question their perceptions and perceived truths of their lived experiences and further play into the experience of fear/pain/anxiety/depression/etc. This experience has been noted by participants to question if what they are enduring is entirely rooted in psychological nature or if the symptoms are evidently physical beyond the valid psychological components found to be associated with AGS in this study. When an individual with AGS feels lost and depleted from recurring neglect and/or abuse, it becomes much more difficult to advocate for oneself or against the opinions of others (as expressed by participants). AGS is a very real allergic response and without the belief or support from others (loved ones, community members, support systems, and medical/clinical professionals), individuals navigating this illness may be at risk for elevated levels of physical and emotional harm, leading to escalating frequencies and ranges of isolating or even self-harming behaviors.

### *Punishment*

The theme of punishment can be understood as an element to AGS which may result from being met with a range of challenging circumstances, including in reaction to encountering resistance and/or repeated instances of negative events/emotions. Punishment consists of feeling like a burden (specifically within their families with feeling shame associated with the desire to protect loved ones) in addition to self-punishing thoughts and behaviors. These thoughts and behaviors have been expressed by participants through numerous instances where the participants either actively sacrificed safety and/or comfort or responded to exposure in self-belittling and harmful actions (e.g., internalizing symptoms, negating to take protective health management actions, excessive self-shaming/self-blame/negative self-talk, disordered eating, isolating behaviors, etc.). When these experiences are confronted or paired with external sources (e.g., being fired due to in inability to work during an AGS reaction or loved ones inflicting blame or doubt onto an individual for their uncontrollable experience), individuals with AGS have expressed the theme of punishment to be more impeding and at times debilitating or harmful to their physical and emotional health.

### ***Perseverance***

AGS alters numerous aspects of patients' identity through distraction, fruitless efforts, fusion/being stuck in thoughts, experiential avoidance (i.e., suppressing unwanted experiences/emotions/thoughts/memories/bodily sensations). How an individual perceives and responds to their circumstances can either result in a strengthening/reinforcement of psychological flexibility or lead to feeling trapped in a rigid and vicious cycle of feeling stuck. In this research, perseverance was examined by understanding how individuals respond to their management of AGS (i.e., noting behaviors/thoughts/feelings/experiences which can contribute to stuck-ness and/or psychological flexibility). This theme includes participant disclosures of the following: preservation of self, motivation, advocacy, exhaustion, compassion fatigue, and burnout.

#### Perceived Stress.

Prior to data sampling, this research questioned if individuals with AGS would display heightened levels of perceived stress (higher levels being associated with higher levels of pain intensity and pain interference). Of the 51 participants who completed the 10-item measurement (PSS-10) within the virtual survey, 22.6% resulted in low scores (2-10), 60.7% scored moderate (12-26), and 16.7% scored high (27-37). Despite the 77.4% of participants who scored moderate and high, it is possible the PSS may not be the most ideal measurement for establishing a narrative for chronic illness. Due to the nature of this illness, many individuals with AGS learn to limit their stress over time as they adapt to what is necessary for survival. This measurement is one which may shift given the resources and coping skills an individual obtains.

Stress is the body's reaction to a challenge or demand. Even with lower levels of perceived stress, it is possible for trauma to remain a barrier in navigating everyday life (Singh et. al, 2021). Given the complexity of trauma which can be associated with AGS, individuals may develop defenses to mitigate stress levels and maintain motivation. An example of this was noted within the individual where the participant stated her relationship with food to be good now that she has been in remission. However, this statement was directly followed by a manic defense of emphasizing persisting trauma with her fear of pork. In this scenario, the participant attempted to deny any alterations or feelings of disturbance by adopting an overly active and/or triumphant position of exclaiming how she refuses to believe her AGS symptoms will return while admitting a prominent fear and behavioral alteration rooted in her experience of AGS trauma.

Certain defenses in response to trauma may also lead participants to experience a numbing of or separation from emotion whilst enduring heightened levels of pain, fear, anxiety, and grief (Baxter, 2022). However, the body can continue to store these emotions despite the perception of them not being experienced (Van der Kolk, 2014). The numbing of emotions was depicted through examples of exhaustion, compassion fatigue, and burnout. When psychological and physical symptoms emerge, individuals with AGS also express difficulty in advocating for themselves, emphasizing the need for supportive loved ones. Within this research, individuals with AGS have displayed their requirements to move forward despite the countless challenges and experiences of disbelief they encounter in daily management and in interacting with their communities. While body mapping participants depicted a power symbol and personal slogan they hold to represent strength and perseverance, the body maps in their entirety functioned as a symbol of perseverance. Participants expressed gratitude for the life-sized maps that serve as a physical object of representation in this acknowledgement and acceptance process.

### ***External Support***

Social support and communities were found to be beneficial in AGS management. This was validated by 88.5% of the 51 virtual survey participants who expressed their management benefiting from social media engagement. In-person participants further validated the value of having a greater personal community and supportive family and/or friends, especially during more difficult and challenging days where negative symptoms/thoughts/feelings/circumstances arise and individuals with AGS approach exhaustion or burnout. Conversely, participants also expressed negative experiences of times where they became disconnected from or lacked external support systems during times of need (e.g., due to a lack of belief or understanding from loved ones, experiencing punishment or blame for reactions, being in isolation while enduring severe AGS reactions, etc.).

This research study became an avenue for external support for those who participated and/or became aware of it. Individuals who were unable to participate submitted messages, emails, and phone calls to the researcher expressing their gratitude and feelings of empowerment for knowing the study was occurring. Additionally, all in-person participants communicated personal meaning in their participation to the researcher (in reflection to all group members and/or in speaking directly to the researcher). For the individuals who contributed to this project through collaboration, they experienced a sense of purpose and empowerment knowing their participation was aiding in helping others find validation in their relatability and journeys with AGS. Additionally, several of the individuals requested art therapy resources from the researcher after disclosing a level of personal healing and transformation from their participation in the study.

## Limitations

The present study sought to establish a narrative for individuals living with AGS. It drew on direct participant experiences through quantitative (virtual survey data) and qualitative (body mapping, an individual interview, and 10-person gathering) to establish correlating and prominent themes through an integration and understanding of ACT theory. Bridging together multiple aspects within this mixed methods research allowed for multilayered findings as well as internal-validity checks, as collected data worked to substantiate the compiled narrative elements to living with AGS. Yet, there are several limitations to address within this research, specifically within the population sample and methodology.

The following limitations were noted by the researcher:

- *Time Limitations:* Due to the relatively short time frame for conducting this research, the researcher was only able to promote and collect participants for the study over the course of a month. This presented challenges in raising awareness and gathering participants (as noted by only filling 3 out of 5 available slots for the art making session and only 1 out of 10 available slots for individual interviews. The individual interviewee was also an individual in remission who is an active advocate for AGS which further limited a more diverse perspective. Additionally, the community conversation was not limited in spots but was later approved as a modification/addition to the initial research application, only allowing two weeks for gathering attendees.

- *Age Limitations:* Participants were required to be over the age of 18 years old thus leaving out the experiences and perceptions of children living with AGS.
- *Gender Limitation*: The vast majority of participants were female, limiting the generalizability of the data to more diverse populations.
- *Familial and Occupational Limitations:* The scheduling of the in-person days was on weekends. This presented a limitation for individuals with children to participate due to needing childcare. Additionally, further restrictions could have limited those with occupational duties on weekends (e.g., individuals who hold on-call positions and/or lower income families who are required to be present at work on Saturdays and Sundays).
- *Location Limitations*: While the researcher aimed to select a location central to hotspots for AGS, the study location presented limitations with accessibility for participants. Participants were required to organize transportation, meaning individuals who live in more remote locations who may have desired to participate may have also been restricted from doing so due to their proximity to public transit making accessibility to the study locations more difficult. It is possible there may have been an increased number of participants if the study allowed for virtual independent interview participation.

- *External Support Limitations:* The study was promoted through social networking sites meaning individuals who did not have Facebook or engagement with AGS associated social media pages or connections via word of mouth were not made aware of the opportunity. Alternatively, those who did participate were individuals who are actively seeking community connection through external support which could influence motivation for participation and/or study measurements (e.g., associated coping skills and stress levels).
- *Filming Procedure Limitations*: The study was promoted with the note of film production. This aspect of the research may have altered certain individuals' willingness to participate due to a lack of desire or increased desire to collaborate in this production process. Additionally, this production process represented a limit in confidentiality. Each in-person participant was required to acknowledge the limits of anonymity within this study while given the ability to keep any of their recordings separate from the final product.
- *Risk Limitations*: Discussion of vulnerable and traumatic experiences is difficult. Thus, the emotional risk associated with disclosure in addition to level of trust and comfort for traveling may have resulted in discouraging the participation of possible participants. During the body mapping session, one participant expressed difficulty in considering her life-threatening and traumatic experiences while displaying clear signs of dysregulation (i.e., watery eyes, trembling voice, change in tone/volume/cadence of speech, removed eye contact, and closed off body positioning). In response, the researcher implemented an additional guided body-scan meditation followed by a series of safety questions and

provided resources in order to minimize risk of harm to participants following their departures.

- *Researcher Limitations:* Research resources are limited within this study. While reference groups were used (i.e., supporting faculty were established in overseeing the project alongside discussion and support from fellow graduate students and colleagues) this was a large project of a single researcher collaborating with participating members of the community in order to compile data and establish the resulting narrative (i.e., creating limitations in validity and researcher perspectives). This researcher experienced conflicts within their role as they identify as an art therapist which presented personal limitations by challenging their valued identity, requiring restriction in their ability to maximize therapeutic outcomes for participants (discussed further under reflexivity). Additionally, limitations arose in background literature due to the lack of research done within this population and the utilized methodologies.

## Validity

To date, there are only two guides for conducting research with body mapping (see Gastaldo et al., 2012; Solomon, 2002) and no other psychological studies on the AGS population. With an overall scarce background literature, this research focused on key comparative factors alongside thematic analysis to acknowledge the participant’s experiences in response to guiding questions. The goal was to demonstrate overarching themes formulated from initial participant data through descriptive and interpretive rigor (integrity and competence). Preserving the participant’s subjective point of view was achieved by acknowledging the context of their shared experiences, highlighting spatial and temporal aspects of disclosures and established social relationships. The subjective point of view (how participants interpret their daily experience of managing AGS) became key for establishing validity and interpretive understanding of this research.

This research design postulated logical consistency through establishing a high level of clarity for the conceptual framework and applied methodology in order to follow principles of formal logic. This allowed for a grounding of subjective meaning within research interpretations. Adequacy to the findings was achieved through determining consistency between constructs and typification of the common-sense experience. Adequacy within this study highlights the use of cross data to bridge validity, ensuring the presented information can be understood and recognizable by individuals living with AGS. Furthermore, participant's reflections and words work to strengthen the face validity and credibility of this research.

This research sought to embed data through formulating relationships across datasets to further support and validate findings. This research nested quantitative survey data within qualitative components (i.e., body mapping, the individual interview, and the community conversation) to validate expressions of qualitative findings. This relationship between datasets was integrated through elaboration and expansion of one another, allowing all participant data to contribute to the established AGS narrative, generating complementary insights and producing a more comprehensive understanding of the lived experience. The artistic practice presented as both a method of inquiry and content while deepening the level of participant reflections and disclosures and promoting empathy/empathetic engagement within the research experience.

The art intervention of body mapping originated in South Africa, and while the use in this study resulted in increased symbolism and language for representation of participant experiences, further investigation into the subcultural and cross-cultural strengths and limitations of body maps is still needed. The subjective experience expressed through participant body maps was verbally explained by the creators, allowing them to be primary interpreters in examining their experiences. Art therapists who were uninvolved from this research study worked to code the artwork, adding a level of validity to the results. While there is confidence in the expression of lived truth and overlapping themes presented across the datasets, there is low confidence in the representation of certain groups within the population such as adolescents and those in more underprivileged positions who may have been bypassed by the medical field and/or individuals who are isolated from support communities. Body mapping displayed strength and validity in revealing narratives of individuals with chronic illness (AGS). Further inquiry will be important to consider and address in extending this methodology across more groups/identities of interest (i.e., nationality, ethnicity, gender and sexual/affectional identities, age, socioeconomic status, health status, etc.).

## Implications for Future Research

By examining the literature review and results of this study, there are clear benefits in art making and discussions of experience with this population. Within this population, many feel invisible and isolated in their struggles, and many feel lost in the cycle of painful symptoms without validation of a diagnosis. Considering future research with group orientation may allow participants to further process and support one another in their shared experiences. Considering a a longer period of time to complete the study and gather participants may increase possibilities for more individuals to benefit from inclusion in the study while also providing increased validity for interventions and results. On the basis of the narratives discussed in this thesis, there are key components which remain unspoken for such as a more diverse population sample (including perspectives of adolescents, parents of children with AGS, men with AGS, lower income families, medical/clinical specialist interactions, experiences of individuals within the support system and community, and spouses of individuals with AGS).

Expanding the meaning of the narrative may also benefit from future research in the following areas:

- How AGS disrupts family systems and impacts interpersonal relationships (e.g., reasons why partners may struggle with coping and/or believing in the experience of individuals with AGS).
- The experience of comorbid conditions with AGS and the interplay of symptoms (e.g., mast cell activation, Lyme, type-1 diabetes).
- The benefits of THC on inflammation, allergic responses, and psychological coping.
- Negative effects of Benadryl and risk for serotonin syndrome.
- How fear or the intricacy of fear is experienced, and the potential of the fight/flight/freeze response affects individuals with chronic illness in their abilities to reflect critically and make management decisions (e.g., self-advocacy).
- Reasoning for why significantly more females than males seem to engage in social media support groups.
- Elaboration and focus on identity shifts associated with AGS.
- A greater focus on the interplay of grief within AGS and chronic illness.
- How self-harm emerges within illness.
- Medically induced eating disorders.
- Understanding how acceptance without defense can be achieved within AGS (i.e., the different types of acceptance, if this ability shifts alongside a sense of control over one's

environment/if feeling a sense of normality is most frequently achieved within the safety of one's home).

- How individuals accept and achieve healthy levels of defense in order to remove added layers of stress.
- How to best support individuals during the time of an AGS reaction.
- Unpacking the different meanings and connections individuals with AGS draw from their range of symptoms and how there may be a numbing of senses to reach somatic acceptance (e.g., if one becomes numb to their sense of smell in public environments due to past trauma and experiences of fume reactions).
- Emotional coping with cultural separation but no displacement (what occurs for individuals who are forced to grieve their culture due to health restrictions while still remaining in close proximity to their communities) and how this may increase feelings and experiences of isolation.
- Establishing a valid and consistent framework for body mapping, rooted in ACT theory.
- How vagus nerve engagement through art interventions can promote healing with complex trauma.
- The psychological benefits of collaborative filmmaking for bypassed populations and advocacy purposes.
- Understanding strengths of mixed-methods research to discover perception of complex trauma and the intricacies of participants' lived experiences.
- Researchers with autism and how this affects/influences the production and evolution of research/projects.
- Psychological benefits of film as a medium for art and research interventions.

## Ethical Praxis

Ethical praxis can be defined as a form of critical thinking where the progression of cognitive elements and physical actions are reflected upon through consideration of their possible impacts prior to implementation. In practice, this begins with the researcher's ethical considerations and the pertinent need to identify cultural sensitivity, fit, and efficacy of study protocols. Necessary IRB approvals, informed consent (explaining the risks and benefits of participation, the voluntary nature of participation, confidentiality, and participants' right to ask questions; permissions rights; relational ethics (what kinds of relationships the researcher intends to develop with participants in qualitative research and how this will be done, inclusion of appropriate expectations), dealing with participants at the completion of data collection (debriefings, making findings and resources available); and the representation and dissemination of findings are all critical elements in promoting positive social change.

In this study, the dictatorship of research questions held the primacy for inquiry. More specifically, the researcher prioritized and embodied the goal of establishing a narrative for individuals living with AGS while simultaneously collecting and analyzing data with respect to ethical responsibilities and needs of participants. Each element of research was employed with embodied theory of art and the art-science continuum in order to maintain the value of underrepresented groups. This research recognized and addressed risks and limitations within researcher and participant roles. As a result, safety plans were implemented to prioritize accessible and strength-based interactions with participants and within the representation of research findings. Dynamic or ongoing consent was observed to combat anonymity concerns, allowing participants to be repetitively invited to disclose what felt comfortable to them with the ability to withdraw consent or disclosures at any time (note: no participants chose to withdraw consent).

**Reflexivity**

Reflexivity is important as it promotes the researcher to acknowledge their relationship between motivations, value judgements, and potential biases (Davis 2020; Dodgson 2019). Given the contextual nature of qualitative research, this researcher was required to consider their role within the AGS community and personally held standpoints in relation to legitimacy and generation of knowledge and value judgements within study and participant interactions. This study was not intended to take on the structure of participatory action research, yet the unfolding of interactions allowed participants to lead discussions in order to promote protection and prioritization of the subjective perspective. Through documentation, this researcher recognized their personal desire to acknowledge and validated expressed pain and hardship, experiencing themes of disappointment where they felt they were restricted in their role from the ability to provide information to participants which was outside of their scope of expertise.

This researcher documented their relationship to the population through journaling and art making, experiencing moments of heavy emotion in processing and reliving the trauma of supporting her best friend in understanding AGS alongside countless life-threatening episodes which occurred throughout their years of friendship and while working on this project. The realization and emotion associated with the fear of losing a loved one to this illness unconsciously became a driving motivation for conducting this research project. The desire to aid and provide thorough information for this population was also driven by the researcher’s background in growing up with a chronic illness and connecting how their engagement with a community, available resources, and advocacy work benefited her management of type-1 diabetes.

The implementation of ACT theory was incorporated for the benefit of participants and aided the researcher’s understanding of self. Through the course of this project, this researcher unveiled a personal defense of turning towards logical understanding in order to avoid sitting/confronting emotion. Ultimately, this research project forced a release of this emotion through a fusion of cognitive thought with somatic memories of AGS trauma held within the limbic system, allowing the researcher to achieve acceptance and healing within their experience of supporting and witnessing a loved one navigate and confront challenges with AGS. The transparency of the researcher’s relationship to AGS provided a sense of comfort for participants and encouraged a mirroring of authenticity and transparency in disclosing personal experiences. Welcoming periods of un-filmed conversion allowed participants to relax into conversation while the researcher worked to minimize the intrusion of filming equipment by only using what was deemed essential for documenting the experience. The production of the film functions as a tool for recognizing the researcher's personal relationship with AGS while directly benefiting the population.

## Film

The film is a direct example of committed action and the strengths of art creation (body mapping and the film itself as an art medium) within this research. Throughout the research process, this researcher has maintained a reflexive approach in considering their positioning in relation to the research. The pragmatic approach to the research process worked to minimize distress while promoting healing, connection, and purpose for participants. The combination of personal human connection with ACT components (The Dilemma of Human Suffering, Present-

Moment Awareness, Dimensions of Self, Defusion, Acceptance, Values, Committed Action) influenced study structure and was found to be successful in revealing a narrative of lived experience for individuals with AGS. The emergence of overlapping themes served as a skeleton for the resulting film. Participant disclosures confirmed a sense of purpose and positive inclusion for individuals with AGS with additional benefits from group participation, art making, and collaborative advocacy film production. The film displays these results in an accessible way, optimizing benefits for the population of concern, while serving as a tool for the researcher's unique healing process.

The contributions of participants as agents and collaborators in this research process can not be overlooked. By making the film accessible on YouTube, resources become more accessible and informative for the AGS population as viewers can connect directly to numerous and beneficial AGS related links/sources within the description section of the video. While serving as an educational and advocacy tool, the film functions to recognize and display relationships with participants, allowing viewers and readers to connect and experience the researcher's role, intentions, and relationship to the work and population. This project and film welcome the observations and implications of ACT theory to optimize research benefits for the AGS population with the goal of supporting and recognizing individuals who may feel lost in navigating this illness.

## Conclusion

This research explored narratives of individuals living with AGS. Psychological context for individuals navigating and living with this chronic illness was established using quantitative survey data and qualitative in-person body mapping, an individual interview, and a community conversation. This methodological discussion has shown how ACT theory can be combined with mixed methods and arts-based research to promote psychological flexibility and healing for participants and the researcher through the understanding of revealed themes (limbic system/physical alteration, fear, grief, confusion, omission, punishment, perseverance, and external support). Through the collaborative data gathering process in survey data collection, body mapping, and exchanged dialogue, validity was maintained within interpretations. Body mapping promoted a deepened reflection for participants in addition to strengthened psychological flexibility through displayed regulation within creative and symbolic art interactions. Each aspect of this research strengthened the criteria of context and rigor through the triangulation of oral, visual, and written data, thereby also augmenting the validity. Furthermore, the collaborative processes and community driven aspects to this research promoted connection and empowerment through participant engagements, providing transparency and trustworthiness of findings. The merging of body mapping with ACT provides qualitative research with an innovative and unique way of understanding the experience of chronic illness, rendering potential for deepened reflections. By prioritizing benefits and accessibility of research for participants and their concerned populations, the act of researching becomes valuable for numerous educational and advocacy purposes while encouraging positive possibilities for advancement of the social research methodology field.

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# Appendix A

## IRB Approval Letters

DOMINICAN
UNIVERSITY
of CALIFORNIA

Feb 6, 2023

Sylvan Streightiff
50 Acacia Ave.
San Rafael, CA 94901

Dear Sylvan,

On behalf of the Dominican University of California Institutional Review Board for the Protection of Human Participants, I am pleased to approve your proposal entitled *Complex Narratives of Individuals Living with Alpha-gal syndrome (AGS). A mixed-methods investigation: examined through self-reported data, in-person interviews, and a group body mapping art therapy intervention* (IRBPHP Initial IRB Application #[11093]) .

In your final report or paper please indicate that your project was approved by the IRBPHP and indicate the identification number.

I wish you well in your very interesting research effort.

Sincerely,

Michaela George, Ph.D.
Chair, IRBPHP

Cc: Victoria Dobbins

**Institutional Review Board for the Protection of Human Participants**
Office of Academic Affairs · 50 Acacia Avenue, San Rafael, California 95901-2298 · 415-257-1310 *www.dominican.edu*

DOMINICAN
UNIVERSITY
of CALIFORNIA

March 1, 2023

Sylvan
Streightiff
50 Acacia
Ave.
San Rafael, CA 94901

Dear Sylvan,

On behalf of the Dominican University of California Institutional Review Board for the Protection of Human Participants, I am pleased to approve your proposal entitled *Complex Narratives of Individuals Living with Alpha-gal syndrome (AGS). A mixed-methods investigation: examined through self-reported data, in-person interviews, and a group body mapping art therapy intervention* (IRBPHP Modified IRB Application #[11093]) .

In your final report or paper please indicate that your project was approved by the IRBPHP and indicate the identification number.

I wish you well in your very interesting research effort.

Sincerely,

Michaela George, Ph.D.
Chair, IRBPHP

Cc: Victoria Dobbins

**Institutional Review Board for the Protection of Human Participants**

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